PMLD LINK
sharing ideas and information

Life is for Living

Spring 2012

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

GUEST EDITORIAL

Life is for Living

The title of this latest issue has led writers to offer a range of different ideas about how to live a meaningful and engaging life, and most of all, how to have fun! We have included a range of topics from arts therapies and Intensive Interaction to holidays, enjoying music and wheelchair friendly boats. We have tried to mix articles that mainly give information about what a particular charity offers (Wheelyboats and Chrysalis Holidays) with discussions around principles (Joy of Sound, Arts Therapies) or how to support living a meaningful life (excerpts from the forthcoming Mencap Guides).

We have included two articles that illustrate the new Mencap Guides that have come out of the Jim Mansell Report 'Raising our Sights'. Mencap have commissioned 11 'How to Guides' to be written on different aspects of improving the lives of adults with PMLD. They cover, personalisation, support for families, advocacy, training, housing, what people do in the day, wheelchairs, communication aids, policies and procedures, and planning and commissioning. The 2 we feature in this issue are 'wheelchairs', by Helen Daley and 'what people do in the day' by Penny Lacey, partly because they have been written by two of the PMLD Link editors but partly because they are particularly pertinent in an issue entitled 'Life is for Living'.

Wheelchairs are very important for people who are physically dependent upon them to get around. Getting the right 'fit' for the needs of individuals is vital, especially if users are going to get the best out of the activities available during the day. The 'What people do in the Day' Guide has lots of ideas for living a fulfilled and enjoyable life but the section chosen for inclusion in this issue of PMLD Link includes Intensive Interaction, stories, Inclusive libraries, drama and theatre and communication in the community. It is mainly about activities that can happen anywhere and everywhere and cost little to implement.

Wheelchairs are also an important ingredient of the article by Rex Harpham from Wheelyboats: boats that are wheelchair accessible. There is a lovely bit of video on the Pamis Freestyles DVD showing a Wheelyboat powering across a lake giving a wonderful sense of speed to the people on board. It is not often that people with PMLD can experience speed except enclosed in a vehicle. On the lake they can feel the wind, the water and the 'G-force'! There is an address to send for the Freestyles DVD at the end of the McDicken and McLaren article).

Alana McDicken and Lesley McLaren from Pamis tell us more about what is included on the Freestyles DVD. Skiing, skating, abseiling are all examples of adapted sports that can be enjoyed by people with PMLD, whether or not they are wheelchair users. Speed is mentioned a couple of times, along with the adrenalin that can be produced whilst doing something exciting. How often do people with PMLD do something that is exciting enough to get an adrenalin rush?! The article contains a lot more, though than just examples of extreme activities. There is a discussion about the physical and psychological benefits of leisure in general and sports in particular. Movement of any kind is really important, especially for wheelchair users who spend so much time in one position.

Holidays are good opportunities to get out and about and we asked Chyrsalis Holidays to tell us a bit about their holidays particularly those for people with PMLD. We (Penny and her husband) have used Chrysalis holidays twice for our nephew and were impressed by way in which they cared for him. He had a lovely time on a traditional beach holiday. Do go to the website (the address is at the end of the article) to find out more.

Although so far we have emphasised the importance of getting out and about to live life to the full, it is also possible to have a good time indoors as well. We have two articles related to the Arts: one about music and the other about dance movement therapy. The music article, written by Robbie Campbell shows how potent music can be in contributing to health and well-being. The charity 'Joy of Sound' is devoted to enabling people with PMLD to join in music however they can. They have made personalised instruments and provided facilitators to lead music making of a profoundly moving nature. Again, this can be seen in a video that is available on the Joy of Sound website (the address is at the end of the article). It is hard not to be moved by the experience as you watch and listen.

The dance movement therapy article was written by Céline Butté, Geoffery Unkovich and Diana Whelan and it includes a description of the work of the Merton Arts Therapy Team with a young woman called 'Janine'. We learn about what dance movement therapy did for her, seeing her move from sitting on the sidelines to joining in and moving confidently in the space. The article also includes the story of a more able person but we have left it in as it helps us to understand the dance movement therapy from more than one angle.

The SMILE project in Oxfordshire is the subject of Celia Chasey's article. The SMILE project is about providing a fun activities for people with PMLD based on total communication, particularly Intensive Interaction. The lovely photographs of the two people enjoying a game with the parachute gives you a flavour of the relaxed and accepting nature of the activities.

Through Julia Rhode's audit of the sensory room in her school, we are given ideas for how to make the best use of multisensory environments (MSE). It is interesting that the most popular use for a MSE in Julia's school is story telling. (But of course, you don't need to have an MSE to be able to tell good stories!) Ultraviolet lighting is also useful in the MSE as it helps to focus people's attention to fluorescent objects that are exaggerated by the UV light. Generally though the ability to control the environment can be really helpful so that people with PMLD can concentrate to develop both their communication and their understanding of the world.

Jill Goodwin's article on what she has gained from spending time with people with PMLD shows how enjoyment is reciprocal. She talks about the best moments shared with people with PMLD leading to mutual enjoyment. It is a fitting place to end this issue of PMLD Link.

Penny Lacey

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NEXT ISSUE

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- Familiy and Friends -

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

If so, contact the editors:
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The copy date for all articles, information and news for the
Summer 2012 issue is the
1st June 2012

Getting to the good-life: the wheelchair

Helen Daly

The provision of wheelchairs, like all aspects of health and social care has been subject to a plethora of best practice guidance, special reports, reviews and policy. Despite this there are on-going concerns regarding their provision. Jim Mansell's report *Raising Our Sights* (Mansell, 2010), identified serious difficulties in the provision of wheelchairs for people with PMLD.

The focus of this commentary is people represented in *Raising Our Sights* who have complex seating needs and are totally dependent on a wheelchair for their mobility and health. A wheelchair is frequently the most important piece of equipment a person has. For this group of people the fundamental truth is: a wheelchair that fully meets the needs of a person will be built on a good **clinical prescription**. The article is based on research conducted for one of the Mencap Guides - coming shortly - aimed at supporting the work of in *Raising Our Sights*.

All policy guidance will say that services must be person centred; all services will say they are person centred; all people supporting the person and process will say they work in a person centred way. Saying and writing person centred, does not necessarily mean it will be person centred. It only happens by doing it. A person centred approach for getting a good wheelchair for a someone with complex seating needs requires particularly focused thought and discussion from all those involved. It is not about just turning up unprepared for a 20 minute chat with a rep from a wheelchair supplier, and choosing a cute, cool colour.

Getting a new wheelchair is often exciting and fun, but it may also involve difficult conversations and choices. It is important that assessments are done in an atmosphere of cooperation, exchanging information and keeping the person at the heart. Having said that, an overview of the legal framework for the provision of wheelchairs can be a useful leveller.

What is the legal framework that should ensure the provision of a suitable wheelchair?

The application of the law can be sophisticated and complex. Nevertheless, having some knowledge of the main legislation is a strong starting point for understanding.

- The National Health Services Act 1977 (NHSA)S 29 and The General Medical Services Regulation 1992 - clearly state that wheelchairs for permanent use are on the list of items that **must be prescribed.**
- The Human Rights Act – states that public authorities must comply with basic Human Rights.
  - ◊ Article 1 The Right To Life - Failure to provide a prescription wheelchair that meets the needs of someone who requires complex seating will threaten their life. Poor seating can lead to serious deterioration in health and even in death. Good seating may slow down or prevent a number of complications including; further deformity, respiratory and urinary infections.
  - ◊ Article 2 The Right to humane and dignified treatment.
  - ◊ Article 8 The Right to a family and private life. People must be allowed the means to have relationships with who they chose and the opportunity for personal development.
  - ◊ Article 14 of the European Convention - The right not to be discriminated in relation to any of the other rights.
- Deprivation of Liberty Act - People cannot be denied freedom of movement without good reason. This could be applied to the actual provision and maintenance of a wheelchair. It also has implications for the use of straps and harnesses. It is important to think about why a strap or a harness is being used.
- The Carers Act 1995 - Carers are entitled to an assessment and their needs taken into account. There is often an issue around the weight of a wheelchair or the provision of a power pack.

Other legal provisions may also apply, depending on the circumstances.

How to have a good assessment

It is important to give the assessment some thought. This is a major piece of equipment that will have long term effects on a person's life. It is a major cost whether supplied by the NHS or privately funded.

Preparing for the assessment

- Think about Outcomes - what does the wheelchair need to achieve? For example: Be more comfortable; Help someone do the things they want to do; Stop someone's head from feeling heavy.
- Jot down a few notes about health (You could use a summary of the person's health action plan) such as; I get chesty; I get sores on my toes. Include any other equipment used, etc. This is the person's health profile.
- Jot down a few notes about what the person does on a typical day: some things the person likes to do occasionally and things the person wants to do. This is the person's life style profile.
- If you have some photographs of the person doing things in their chair, pick a few out and take them with you.
- Try and find out what could be available
- Include the person in all the above!

What should be expected at the assessment appointment for someone with complex seating needs?

Good assessors will be interested in the person, how they live their life and how the wheelchair helps every day. The appointment is a conversation and medical assessment about the person's needs.

If the person has complex needs you will need:

- Enough time for the assessment - this could be as long as 2/3 hours.
- The assessment conversation to cover the person's health, their lifestyle and some vital measurements about joint range and overall body condition should be taken account of. The measurements will help to provide evidence about the person's posture and movements.
- For some measurements the person will probably need to get out of their chair and onto a physio plinth. The assessment centre will need proper equipment such as a ceiling hoist and physio plinth.

Who should be in the team doing the assessment?

This will depend - but the core team should include:

- the person and a familiar, skilled care giver
- a lead assessor - qualified and experienced in postural care, neurodisability and rehabilitation.
- a technician qualified in rehabilitation.

In some assessments there may also be a need for a clinical scientist, speech and language therapist and an electronics engineer. For example on a power-chair or smart-chair, it will be important to get any switches and electronics in the right place. Everything will then come together in one complete integrated system.

It is important that everyone gets on - sometimes these conversations can be difficult. There may be tensions between different outcomes - making the assessment, prescription and provision more complex. See below for examples of this.

Making difficult decisions

Compromises are not always about money. For people with complex needs outcomes should be a chair that:

- is comfortable
- helps ability and independence
- minimises complications - including secondary/ future complications
- supports care giving
- is part of a whole lifestyle

Below are some examples of how outcomes may conflict and difficult choices made:

i) Comfort verses independence

For example a wheelchair may need to be tilted back for periods of time and this may inhibit the use of a switch or there may be a temptation to try and correct a posture to gain back a skill, when for comfort accommodating the current posture is best.

ii) Independence verses prevention of secondary and or future complications.

This can be illustrated by Jim. Jim was learning to tolerate a headrest for longer. The young man was good at giving eye contact to speakers and used to looking around to fix his eyes on whoever was talking or whatever was interesting. This supported his ability to understand and communicate with the world. However, over time this could interfere with his swallowing function as his neck was becoming progressively out of line. These are really difficult issues to resolve. They illustrate why both clinicians and carers need to have open dialogue.

iii) Care givers' need for a lighter chair verses the need for a robust chair because of strong spasm.

Care givers themselves frequently develop problems due physical handling - even where risk has been reduced as much as possible - a future cost to the NHS and care giver. It may be possible to solve this by providing a rigid frame, or if possible reduce the size of the frame, reposition the pushing handles - or consider a power pack to help.

After the assessment appointment

The lead assessor should write a report setting out what they found and what someone needs. The people who should get copies are the person and appointed carer, GP and whoever is funding the chair.

The number of appointments will depend on the seating a person requires. Some wheelchairs can be issued right away, some will take a further appointment for fitting and Issue - people with complex needs may require at least 3 more appointments. When funding is agreed a prescription can be written for the chair.

Can I have a power-chair or smart-chair?

Powered-chair - a chair that uses a motor to move. Smart-chair - a chair that has additional electronic features. See also below

Powered-chairs and smart-chairs are often used in school and childhood. They become an important part of people's independence and health. A lack of understanding is sometimes cited as a reason why they cannot be supplied to people with PMLD.

A blanket ban on smart-chairs for people with PMLD could ignore article 8 of the Human Rights Act. People have a right to a private and family life. They have a right to personal development and independent movement as far as possible.

When considering Smart technology:

- have an expectation that clinicians and others should be sensitive and knowledgeable regarding the small but highly significant ways people with PMLD are able to express and control their world. People will spend many hours each day waiting and being moved. Anything that gives a person a sense of control over when they move and/or supports movement will be very high prized by the person.
- point out that independence in this context is not about driving an electric chair unsupervised from place to place. It is nuanced and meaningful to the person involved and is fully person centred.
- give a few examples how smart-chairs may be appropriate for people with PMLD eg: sitting to standing chairs, chairs that run on track systems or have stop sensors, pre-programmed chairs to run along a specific path, chairs that allow people to be at different heights or angles.
- a chair and switch that allows someone to experience movement and make a connection with the switch and the movement - even when this is hand on hand is an example of person's independence and development.
- argue that computers and pieces of equipment are provided for all sorts of people - who may only use a few functions - this should be no different for people with PMLD.
- If a person qualifies for a power/smart-chair they are also allowed a manual chair. Both chairs must meet the needs of the person.

Campaigning for and championing Good Services - what is needed

Based on research and reports the following seem to be key:

- highly ***specialised wheelchair*** services for a range of people with neuro-disabilities who require complex seating solutions. Within each Health Authority this will be a small number of people, including some with PMLD. Provision of the correct chair is about good training in 24 hour postural management, complete multidisciplinary teams in wheelchair assessment and provision and maintenance teams who work closely together. It is also about ways in which services can develop capacity and volume to enable skills to be fine tuned and sufficiently practiced. General wheelchair services tend not to have the number of people needing complex seating for staff to fully, regularly implement highly specialist training.
- recognising everyone's skill and potential. People, as reported in *Raising Our Sights,* often suffer ***discrimination*** 'with knobs on'. Respect small but **significant** ways in which people are able to; make choices, take part in the world, achieve new learning and skills - including maintaining learning and skills and have independence despite the need for someone to accompany them. This is particularly pertinent with regard to the provision of electrically powered chairs or even higher spec manual chairs that open up people's lives.
- ***respect Human Rights*** when delivering or receiving services. They are a central pillar in protecting everyone and supporting all to build a society worthy of pride. Good seating saves lives - article 1, it optimises health and provides people with dignity and respect - article 2 - and gives people a right to a private life by helping them mix with others and gives opportunities for personal development - article 8.
- actively be and expect a ***person centred***, holistic approach with guaranteed funding. It needs to happen - services need to do it - don't just say it.

There are always lots of comments about multidisciplinary, person centred approaches - usually locked into comments regarding joint funding. Joint funding is more problematic in adult services. Firstly, education, a potential funding stream, is not usually available. Secondly, adults tend not to attract the same charitable funding. Thirdly, adult social care, the most likely partner, is poorly funded and people are frequently expected to contribute towards services from incomes that do not meet the Minimum Income Standard for an inclusive life (as defined by the Rowntree Foundation annual figures this does not include disability related expenditure).

- making ***difficult choices*** because of the very nature of the complexity of needs. This can be very distressing requiring careful and sensitive handling. Be prepared for open and full conversations.
- underpinning all above should be ***good data, good communications and the right mix of expertise.***
- a clear and unambiguous understanding- ***at the* core of the best wheelchairs - is a good clinical prescription.**

Contact Details

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Family Carer

Further reading

Department of Health (2010) *Local Innovations in Wheelchair Services* Published to DH website, in electronic PDF format only. http://www.dh.gov.uk/publications

All Party Parliamentary Group for Paediatric Mobility Reform (2010) *Wheelchairs is my shoes: Making the case for wheelchair reform* Published by Whizz-Kidz. Available from www.whizz-kidz.org.uk

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What People Do in the Day

Penny Lacey

I was asked to write one of the guide booklets for Mencap following the 'Raising our Sights' Report from Jim Mansell. This guide is called 'What People do in the Day' and it is made up several different sections. I have selected a small part of the section on specific activities to share with you in this issue of PMLD Link. There are several other sections in the guide but you will need to get the guide to read the rest! I selected the Communication and Interaction section as it is fundamental to the idea that 'life is for living!'

Communication and Interaction

This section contains some principles and specific ideas for ensuring that communication and interaction with people with PMLD is likely to engage them in a way they can join in. The first example concerns using the principles of Intensive Interaction in a swimming activity. It illustrates the importance of getting the communication and interaction right for this person.

Clare attends Oxford City Day Time Support services and has been coming here for 5 years. She is in her early twenties and quite physically able (she can walk confidently but often needs an arm for support), but she does not communicate with speech. For the last 3-4 years we have been working with Clare in more and more ways that are influenced by intensive interaction. She has also been taking part in intensive interaction sessions, but our focus has been on improving the quality of our day-to-day interactions with Clare, bringing significance to each and every communication. I have been going swimming with TC once a week, on-and-off for the last 9 months.

Sometimes the smallest things (like a change in the music) can agitate Clare and can lead to her demonstrating distressed behaviours such as raising her elbows above her head, screaming, or fixated gazing at someone or something (often her own hands). Getting into a busy swimming pool, getting changed, walking barefoot around the swimming pool area etc. presented a real challenge for Clare at the beginning, as routine and the security of a known and familiar environment are crucial to her. But over time, by ensuring a constant focus on Clare's changing states and moods (by watching her facial expressions, her body language etc.) throughout the whole swimming experience, I believe Clare has moved on from finding the swimming experience enjoyable (but challenging), to genuinely loving every minute of it.

Hanging Out Project (HOP)

Sheridan Forster, in her 'HOP (Hanging Out Programme)' recommends 'spending 10 minutes interacting with a person, giving them 100% of your attention'. HOP is not hard to do but it does require the supporter to switch off from the housework and the cooking and just 'chill' with the person with PMLD. Of course, the housework and the cooking can be really good opportunities for interactions, where the importance of doing something together is greater than the product of the activity. You can download the HOP booklet from (www.cddh.monash.org/products-resources.html).

Although Intensive Interaction or HOP conversations require little organisation beyond providing an empathetic person with whom to interact, there are other activities that focus on communication with people with PMLD and these require a little more thought and preparation.

Story Sharing

There is a range of ways of sharing stories with people with PMLD. Involving people with PMLD in story telling is usually multi-sensory and is unlikely to focus on a book, although the story may originally have come from a book. The multi-sensory experience of story telling is likely to involve objects to touch, look at and listen to; things to smell and even to taste. Suitable stories are usually only a few sentences long, with each sentence being repeated several times to help the listeners to become familiar with them and learn to anticipate what is coming next. Stories often have a surprise in them, which can be anticipated once the story is well-known. Stories such as Greek myths or legends, classics novels, Shakespeare plays: anything that can be retold in a simple fashion can be suitable. Episodes from stories can be fruitful for little interactive games.

A group of young people with PMLD were playing interactive games inspired by Dickens 'Oliver Twist'. The book is not accessible to them but some of the ideas and emotions involved in the book are accessible. One of the people with PMLD had a glittery handkerchief half hanging out of a pocket and he walked slowly round the circle of his friends until one was supported to pull the handkerchief from the pocket just as the rhyme finished. The rhyme is chanted in a fashion called 'call and response' with the leader saying a line and the supporters and anyone else who can, repeating it back. The whole episode is very involving and the young people get excited as the 'Oliver' learns to pick Fagin's pocket.

This interactive game comes from a book by Keith Park called 'Interactive Story Telling' (published by Speechmark) and it contains many more.

Personal stories can be very successful, especially if they are based on something funny, a happy event or a sad situation that has happened to the person with PMLD. For many people with PMLD, adding multi-sensory resources to this personal story can mean it is can be retold many times.

Rebecca was asked to 'tell her story' to the people at the launch of the Mencap campaign for PMLD accessible toilets in the community called 'Changing Places'. She is able to do this with support from her mother and a series of objects which were kept in a basket. Her mother took the objects out of the basket one-by-one to the delight of Rebecca who nearly jumped out of her wheelchair in excitement. Her mum produced the car keys, her purse, Rebecca's hat and gloves, a bag and a mug one by one as she told the story of why Rebecca likes to go out and about and thus needs a Changing Places toilet to enable her to stay out all day.

This story was told for a particular event but it could be told many times, anywhere. Writing little personal stories can be quick to do and can focus on the objects and sensory resources particularly liked by an individual with PMLD or on a specific event that is memorable.

Nicola Grove was filmed telling a story in a residential home with a small group of people with PMLD. The previous day the residents had made some chocolate cakes and one of the supporters had left the oven on too long and the cakes had burned. Nicola took this event and turned it into a story that can be retold many times, using the hard burned cakes and some new soft cakes as props along with Makaton signing and a dramatic tone of voice.

Stories can be very powerful and can be told almost anywhere at any time. They work because they can be repeated many times and the listeners can become more and more familiar and thus more and more involved in them. If you want to know more about story sharing then try Nicola Grove's book 'Learning to Tell' (published by BILD).

Inclusive Libraries

Public libraries are gradually becoming good places to visit for people with PMLD. For example, Bradford, Leeds and Birmingham have specifically developed services for people with learning disabilities in their central libraries. These services include story and activity sessions and the use of a touch screen computer with accessible software. Other libraries are becoming more aware of the needs of people with learning disabilities and are open to discussions about how they can meet the needs of individuals.

Bag Books is a charity whose main activity is to design and produce multi-sensory books. Many public libraries have bought some of these books and have a system for lending them to families and residential homes. If your local library does not know about them then you could print off information from the Bag Books website and take it in to show them what you want. The website is www.bagbooks.org.

A small group of people with a range of learning disabilities went from their day service to Birmingham Central Library for a story session around 'The Tempest'. It was run by the music library staff who chose different pieces of music to accompany their multi-sensory experience. A few episodes from the play were selected for their dramatic quality and great fun was had by all!

Drama and Theatre

Much of the story sharing, Bag Books and the activities in libraries are based on interactive drama. People with PMLD are directly engaged with the action and resources. Actual theatre experiences can be accessible to some people with PMLD, depending on how aware they are of their surroundings and how much they enjoy watching. Shows that primarily employ music and dancing can be accessible, particularly shows that are written for young children. Usually these are lively, noisy and engaging.

Peter, who enjoys watching the television, was supported to go to 'The Snowman' at Birmingham Repertory Theatre. It was clear that he enjoyed the show and although he was not completely silent throughout, his repetitive phrases were many fewer than usual. He is able to say 'Snowman' and he repeated that to his carers on many occasions, following the show. Peter now regularly goes to the pantomime and other family shows.

Communication and interaction are at the centre of everything people with PMLD do in the day. The examples in this section have shown how sometimes the interaction is the reason for the activity but sometimes the activity is to be involved in a sport, arts or leisure activity.

There are several providers around the country who focus on communication and interaction. For example Us in a Bus in Surrey (www.usinabus.org.uk) and the SMILE project in Oxfordshire (see the article in this issue of PMLD-Link). This example is from Us in a Bus who provide a home service.

Jeannie doesn't use language, but does make sounds and sometimes seems to relax when we sing. What we might do is 'echo' her sounds back to her, letting her know that we've noticed her and are responding in her language. This can develop into a conversation without words, playing with volume and pitch and pauses. Jeannie can become more confident at this stage and may even let us touch her hand or ruffle her hair. – sometimes she'll even let us massage her feet with aromatherapy oils.
On another occasion we might sing a song that we've noticed Jeannie has relaxed to before. But we want to make this an interactive experience to help Jeannie get the message that that she can be in charge of what we do together. So what we do is pause after the first verse and tell her that when she makes a sound, we'll know she wants us to carry on. When we first did this we didn't know whether Jeannie would understand, or whether her sounds would be random or deliberate. Now her responses are clear and consistent; she looks alert and leans forward at the end of each verse and we are sure she knows she is in charge of our singing. This can be an empowering experience and it's what we are aiming for with all our clients, whatever activity we are sharing.

Communication in the Community

It is really important that people with PMLD have opportunities to communicate and interact with their neighbours and friends in the community. As can be seen from the story below, it is possible to create meaningful employment for someone with PMLD. The two next stories come from Grapevine, a charity in Coventry that 'helps people with disabilities to grow their lives'. (www.grapevinecovandwarks.org)

Ann has a job which enables her to move round her local community and meet her neighbours. With support, she provides a library service for magazines. She has a hand pulled trailer for the magazines and walks around from house to house. Her clients chat with Ann and show their appreciation of the service she provides. They also greet her when they are out shopping and she shows pleasure at the interactions.

Desi attended a steel band concert and his supporter noticed how much he enjoyed it and asked if Desi could attend the band practices. This was a new idea to the band but they took it up and Desi attends band practices regularly. He has become part of the group and everyone misses him if he can't attend.

Attending religious services (church, synagogue, temple, mosque) can also increase the communication and interaction in the community.

Julie loves going to Coventry Cathedral. She moves gently to the music and makes little happy noises throughout. When the organ is playing the closing piece she moves down the centre of the cathedral towards the sound, obviously enjoying the experience. People greet her and chat with her when the music has finished and she wanders round from person to person.

Amerdeep goes with his family to the Sikh temple at 6pm every day. He is welcomed by the community and joins in as much as he can. He enjoys the routine of the process, the prayers, the music and the calm atmosphere.

Conclusion

Hopefully this article has not only given you a flavour of the Mencap Guide 'What People Do in the Day' but also some ideas for communication activities. I have tried to demonstrate a range of activities, most of which are simple to do. These activities need the focused attention of supporters but are not difficult to achieve by anyone wanting to interact with individual with PMLD. Activities in the day do not need to be complicated to be enjoyable and engaging.

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www.bagbooks.org

www.usinabus.org.uk

www.grapevinecovandwarks.org

Wheelyboats and The Wheelyboat Trust

Rex Harpham

I first became involved with the Wheelyboat Trust about 11 years ago after seeing a small article about their work in a waterways magazine. I was working for Devon Social Services at the time as a community resource worker for adults with learning difficulties many of whom also had physical disabilities. I was 17 years in the role and retired 6 years ago. I wanted to expand the range of activities in which the students at our day care centre could engage and the possibility of becoming involved in water-based activities provoked much interest.

The Wheelyboat Trust was founded in 1984 (then called the Handicapped Anglers Trust) and began its work in 1985 supplying wheelchair accessible boats mainly to fisheries for the benefit of disabled anglers. Angling is still an important activity for the Trust but the role of the Wheelyboat has developed far beyond the fishing lake and the Trust changed its name in 2004 to reflect this wider remit. The original Wheelyboat model was a very basic square aluminium craft with a flat bottom but its principal feature, a bow door that lowers to form a ramp for wheelchair access, is common to the later more sophisticated multi-purpose models. These are the Mk III and Mk IV which seat 8 and 12 respectively, including wheelchairs. Both have drive-from-wheelchair helms which mean disabled people can participate fully in the boat's operation.

When I first came across the Trust the Mk I had been superseded by the Mk II and for the first time the Trust had a Wheelyboat large enough to provide a useful multi-purpose role, namely pleasure boating and nature watching as well as fishing. It was about this time that the Trust started supplying Wheelyboats for a wider range of activities which is why I became interested in its work. I have been a regional volunteer for the Trust since 2004 and have helped the south west become the busiest region for Wheelyboats with a multi-purpose role. There are currently 13 of them between Dorset and Cornwall and all of the large inland lakes (where boating takes place) operate them.

To date the Trust has supplied nearly 150 Wheelyboats all over the UK and Ireland. Its main role is to help public waters, groups and organisations acquire Wheelyboats for the benefit of their visitors, members, beneficiaries, etc. It designs and develops Wheelyboat models, commissions boat builders to manufacture them and fundraises to help venues and groups acquire them. At the moment it is working with Countryside Mobility South West (a pilot project funded by Natural England 'Access to Nature' scheme and the Big Lottery Fund) to supply four Wheelyboats to waters here in the south west. One has already been launched (on Tamar Lakes near Bude) and the other three are currently being built (for Haven Banks OEC in Exeter, for Maunsel Lock Canal Centre on the Bridgewater and Taunton Canal and for Wareham Boat Hire on the River Frome).

Wheelyboats are designed especially for disabled people and in this respect they do a very good job. However, the people I worked with in social services and those I still look after as a part-time carer have quite complex needs which even the specially designed Wheelyboat may not entirely meet. Wheelyboats are mainly self-operated craft and are effectively 'on hire' to disabled individuals families and groups at their respective venues. They are relatively small craft (the Mk IV is the largest at 21' long) and as such there is limited space on board, particularly for larger and heavier wheelchairs.

There are times when the people I look after need access to a loo there and then but a loo is not a feature likely to be installed on a public Wheelyboat in the near future. They are very stable boats and the handrails can be built to whatever height is needed but as they are available for public use their design has to satisfy the majority of needs and that could include fishing in which case handrails must not be too high. Higher handrails clearly give disabled people who are unsteady on their feet a greater feeling of security and are an essential factor for the safety of people who are prone to fitting. Wheelyboats are mostly uncovered but some people need shelter from the sun as much as they do the rain. Covers are easy to fit on Wheelyboats and I do think that some venues could do a little more to consider the more complex needs of people with the type of disabilities I look after.

Without exception, everyone I have taken out in a Wheelyboat has enjoyed the experience. Some can communicate quite well but those that cannot make all the right noises of approval when they are out. What is particularly enjoyable is the motion of the boat going forward and riding over the waves (which generally on an inland lake are quite small but you can enhance the experience by turning and driving back over your own wash). It is important that they are provided with a comfortable seat and are kept warm and dry.

Wheelyboats have been tremendously beneficial to disabled people and have been a wonderful innovation but they are a compromise and no single facility can meet the needs of all its intended users. Most venues have just one Wheelyboat which has to serve the needs as much as it can of all visitors to the venue. However, as the Trust also helps groups and organisations acquire Wheelyboats, these boats have much more scope for individual tailoring.

Getting out and about on water provides me and my charges with some wonderful experiences. I would heartily recommend them but please do a little research before turning up and taking one out. Find out your nearest venue, speak to the operator and even pay a visit first to assess the craft's suitability for you.

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For more information about the work of the Trust and a national list of Wheelyboat locations, visit the Trust's website at www.wheelyboats.org/

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Active Lifestyles: Enjoying & benefitting from leisure

Alana McDicken and Lesley McLaren

The health benefit of leisure for the general population is well known. We are all encouraged to take up physical activities and sports to both improve our health and our well-being. Regardless of our individual abilities, we all have a cardiovascular system that needs regular exercise to help it maintain and improve. Regular exercise has many other significant benefits that together help improve our quality of life. It helps our bodies perform and rest better. Using muscles, helps them to grow and develop; bone density increases; respiratory systems work more efficiently; ligaments and tendons become more flexible; bladders and bowels become more regular and comfortable. In addition, our brains release endorphins when we are taking part in an activity that is challenging and appropriate.

The benefits of leisure for people with disabilities have also been well documented (Lancioni and O'Reilly1998). However, all too often it is assumed that people with profound and multiple learning disabilities (PMLD) cannot stay active. Yet there are a number of healthy activities that this group can participate in and enjoy with their families and friends. Tohill and Laverty's (2001) study of incidence of bone fractures amongst a population with intellectual disability focussed on three main factors most relevant to this population: diet, amount of sun exposure, and mobility (see also Valiant and Nugent 2006). Most people with PMLD spend a very high proportion of their lives in wheelchairs and indoors. A number also require a liquidised diet or receive all nutrition and medication non orally making it more difficult to obtain calcium and additional Vitamin D through diet/food. All of these factors leave people with PMLD at high risk of brittle bones through osteoporosis, because of their immobility and their lack of exposure to sunlight. Resistance activities help muscle tone and being outside in the fresh air helps production of Vitamin D and lifts the spirits. Recent reports in the media highlighted the low levels of Vitamin D in a high proportion of residents in the UK and most notably in Scotland (Zgaga et al, 2011). This led to the Chief Medical Officer for Scotland writing to health professionals in Scotland to raise awareness of the importance of this issue (http://www.scotland.gov.uk/Topics/Health/health/Health/EatingHealth/vitamind/CMOletter).

The psychological and social benefits of activity are an increase in self-confidence that can develop by building new friendships and being actively engaged, physically and intellectually, in an activity. Increased interaction with others and feeling truly part of something, be it an activity or community, enhances the sense of well-being for people with PMLD and their families. The challenge and fun of exercise can also help to avoid frustration, which can be displayed in difficult behaviour.

SOMA (Sporting Opportunities for Motor Activities) was developed to meet some of these challenges by enabling athletes with profound and complex disabilities to participate in motor based activities. These are specially adapted to stretch their abilities and to compete with others of comparable ability. PAMIS in partnership with Dundee City Council Disability Sports Team has set up the SOMA Club in Dundee which is run on a monthly basis. Not only does this benefit people with PMLD but it also involves their families in exercise and activity, which is also extremely important. Carers often find it difficult to find the time to get out and exercise and are at risk of becoming unfit, isolated and depressed. Physical activity really does benefit the whole family!

The history of PAMIS' leisure work

Since its inception in 1992 PAMIS has successfully run a number of inclusive leisure projects, beginning with Leisure for All 1997-2000 (Thomson, 2004) and more recently, Healthy Lifestyles, a three-year programme focussing on the health needs of people with PMLD and their families. As part of Healthy Lifestyles, PAMIS worked with families and leisure staff to develop a range of inclusive indoor and outdoor sports and leisure activities for people with PMLD and their families in their local communities. Three years on from the end of that project many of the activities initiated are still running. Work continued through 2009/2010 which culminated with the production of the Freestyles pack and DVD in January 2011. Freestyles demonstrate that with enthusiasm, commitment and imagination, people with PMLD can be "out and about, delighting in new sensations and achievements". Currently in Glasgow the Accessible Leisure project continues to promote the needs of people with PMLD and their families to leisure and sports professionals. It helps them to source accessible activities and venues in the local area and run 'taster' sessions for people with PMLD and their families. Families who attend the Accessible Leisure project's events also benefit from informal support from other parents, carers and siblings of someone with PMLD.

Barriers

There are a number of challenges to be met when sourcing and providing inclusive activities. There are issues of access which need to be overcome; often venues, equipment and techniques require a degree of adaptation to make them suitable for someone with PMLD. Often only slight adjustments, such as involving an extra member of staff, can overcome initial difficulties and open up an activity to someone with profound and complex disabilities. However, there are activities that require more adjustment with the need for specialist equipment, advanced or alternative training for staff and most importantly, adaptation to the actual activity to make it both physically and intellectually accessible. These challenges are not insurmountable if ways and means are demonstrated to the leisure providers showing what can be achieved.

A significant barrier which deters people with PMLD and their families enjoying a more fulfilling social life is their need for fully accessible changing places toilets and the lack of such facilities e in our communities. Recent research (Hogg, 2009) estimates that around 230,000 people with disabilities need to use Changing Places toilets, around 37,000 of these are people with profound and complex needs. The lack of suitable toilet facilities often results in outings being limited to a small number of places and for only short periods of time or not at all. If families knew there were suitable facilities available for their relative with PMLD, it is likely that they would have more confidence in accessing a wider variety of activities and facilities, thus improving the overall health and well-being of the people they care for.

Leisure providers often lack awareness of the needs of people with PMLD and are not aware that they could and would like to participate in leisure and sporting activities. Often all that is required is some additional staff training and a positive, enthusiastic approach to open up a new activity. Whilst PAMIS continues to promote to leisure professionals the possibilities for opening up their services to people with PMLD, this is on the whole very difficult to maintain. Examples of good practice are short lived and dissipate unless there is an individual who works to continue to offer accessible activities independently.

Range of activities

Over the years the PAMIS leisure projects have offered a range of accessible activities to families. Some of these have included adapted cycling, adapted water sports, horse riding and carriage riding, SOMA (Sporting Opportunities for Motor Activities) and a range of outdoor adventure activities such as speed boating and abseiling.

In the Glasgow area PAMIS has organised a number of adapted skiing events, where fully qualified ski instructors support people with PMLD to ski using appropriate equipment (e.g. sit ski) on both dry and real snow slopes. This activity provides the opportunities for people with very complex disabilities to experience a real adrenaline rush and a sense of freedom which may be a brand new experience for many. The most recent adapted skiing event was held indoors, on a real snow slope. This provided a true to life sensory experience for participants. Skiing is an activity that many of the families believed was beyond their relative's reach, both in terms of their ability and financially. The venue also had a large toilet facility where an adult size changing bench and hoist were provided. By providing this opportunity, families, venue staff, members of the public and other skiers were able to see that someone with PMLD could successfully take part in this activity and enjoy it the same way their fellow, able-bodied skiers can. The feedback given by families and participants following this event was very positive:

"The session was great, the instructions were given clearly…K enjoyed himself so much he would've loved a longer session"
(Parent, Event Evaluation, October 2010).

"Following the PAMIS snow sports sessions we've continued taking Neil for skiing sessions at Xscape, very successfully. This is just one of the ways we have been able to open up new possibilities for Neil, thanks to PAMIS".
(Parent, Event Evaluation Form, December 2011)

Wheelchair ice-skating is a simple but exhilarating experience for people with PMLD – the combination of the cold and speed is very popular with many who participate. All that is needed is an enthusiastic carer or volunteer who is needed to push and control the wheelchair across the ice and an accessible ice rink. Whilst not all ice rinks are accessible more are making adjustments to increase accessibility. In some cases, ice rink staff just need to be presented with the possibility! There has been a number of successful wheelchair ice-skating sessions arranged by PAMIS in venues around Scotland. There is a weekly session that continues to run in Dundee which is attended by up to 20 wheelchair users and their carers. This group choose to book a dedicated area of the ice rink for their session, alternatively open, public sessions can be accessed at some rinks. Such a session was arranged through the Accessible Leisure project in Glasgow, in December 2010, which saw eight people with PMLD skate with their parents, siblings, paid carers and members of the public. This was a great opportunity for people with PMLD to be fully engaged in an activity surrounded by and interacting with able-bodied skaters. Parents/carers also reported how much they enjoyed it and were surprised how much exercise they got from taking part. It was an activity that all the family could take part in equally. This skating session was definitely enhanced by two experienced skaters (one skating staff member and one paid carer) who were able to provide wheelchair skaters with “speed skates” around the rink which seemed to increase everyone’s adrenalin! All the wheelchair skaters responded positively to the experience.

Next steps

Whilst there has been some progress in increasing accessibility to leisure activities it has been fairly limited and the long term sustainability of these activities has been poor. Leisure professionals within community facilities need to play an active role in the organisation, promotion and on-going provision of accessible leisure for people with PMLD. Unfortunately, there are too few examples of this. Without specific leisure projects, such as Accessible Leisure, all too often leisure activities for people with profound and complex needs quickly disappear. Far more work is required in this area to inform mainstream leisure providers about the needs of people with PMLD and their desire to take part in a variety of pursuits. Over the next year of the Accessible Leisure project, PAMIS, together with family carers will continue to lobby community sports and leisure services to be more inclusive. By demonstrating what can be achieved and seeing the obvious enjoyment of the participants we hope to change many hearts and minds. PAMIS would be interested to hear from other projects or individuals who have experience of overcoming these barriers.

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Chrysalis Holidays

Micah Hampson

For the past two decades, *Chrysalis Holidays* has been at the forefront of innovative themed and educational holidays for adults with learning disabilities in the UK. Starting from a small ground-breaking programme of short breaks in the summer of 1991, *Chrysalis* now offers a comprehensive range of holidays throughout the year and across the continent. Contained within its charity mission and remit is a commitment to welcoming all guests, regardless of ability or disability. Since the company's conception, it has run a 'Special Care' programme for customers with more profound disabilities. These holidays are staffed at a higher than 1:1 level and focus on nurturing the five senses.

I talked to Andy Hammond, an experienced holiday manager from Chrysalis, about the service they provide for people with profound and multiple learning disabilities:

Q – Andy, how long have you worked for Chrysalis and what do you enjoy most about your work with guests with more complex needs?

A – I Joined the Chrysalis Holiday program almost 4 yrs ago now. The best thing about working with people with complex needs for me, are the small things like when a guest smiles or laughs for the first time in your company the small changes in body language and facial expression that tells you you're doing something right.

Q – Where do your customers with profound disabilities come from?

A – Mainly from the North West of England. We happily take customers away who hail from all parts of the UK, but sometimes the cost of transport is prohibitive to customers from further afield.

Q – What are the main difference between your 12-person group holidays and 'Sensory' programme?

A – Our 12 person holidays are focused on providing fun and entertainment that meets the needs of a group. In our sensory programme we have a greater staff to client ratio which allows us to make person centered plans and meet the needs of an individual. We are not confined within a theme or have any time constraints. We can spend as little or as long on each session depending on what's right for the client.

Q – How do you ensure that your customers are getting the correct support?

A – Before anyone comes away with us for the first time we complete a home visit assessment where we work through all the necessary care plans and risk assessments. This gives us an opportunity to meet the guest in their home environment and to talk in detail with full time carers. We also request copies of any individual care plans that people might already have, and are in regular phone contact if any concerns may arise. We will never be able to acquire the same level of support knowledge but we have many checks in place so we can get as close as we possibly can.

Q – What extra challenges do you face in providing holidays for people with PMLD?

A – Without extensive service user knowledge it can take time to get to know a guest and if a guest cannot verbally communicate their wishes to us (although we will try many forms of non-verbal communication) there sometimes can be difficulties in knowing what those wishes are. We understand that this may be frustrating to our guests and work with full time carers to try and minimize this frustration.

Q – To your knowledge, how does your service differ from that of other companies?

A – As far as I know, not many other companies provide holidays for people with complex needs. It requires a much higher level of staff training, resources for mobility and care aids, and a more time-consuming support assessment, which I think deters many other companies in our industry.

Q – Do you get repeat bookings for your sensory holidays?

A – Yes, the vast majority of customers will return; some have a number of holidays with us each and every year. As well as producing a caring & rewarding experience for customers with PMLD, we are often providing a valuable respite service for their full-time carers at home.

Q – Are there any differences to the training methods and requirements in to enable your staff to support customers with complex needs?

A – Not really differences in training as guests with less complex needs may still have difficulties in communication, mobility and personal care. Our staff are trained for all eventualities. But there does need to be a difference in our staff's mental approach we need to be more flexible, more patient, open minded and have the ability to think outside the box when stimulating and engaging our guests.

Q – Can you give me a few examples of outings and activities particularly suited to PMLD guests, and how you measure the success of these?

A – Sensory and relaxation sessions that may include soft play, sensory stimulation, massage and aromatherapy as well as hands on music or arts and craft. We may go swimming, dancing or take a walk on the beach, or possibly something a little faster paced like a theme park or speedboat ride. The success can be managed differently on an individual basis: it may be something like a guest showing signs of pleasure during the activities, an increase in participation over a period of time or an improvement in behavior. Every guest is different and there is no one generic way to measure the success of our activities.

If you would like to find out more information about Chrysalis visit www.chrysalisholidays.co.uk

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Musicking with Joy of Sound

Robbie Campbell

It's a cold winter morning in Vauxhall and I find William outside the Heritage Centre where the music session is to take place, clearing leaves from the entrance. I introduce myself and am simultaneously greeted and drawn into conversation about what he's doing. He emphasises the importance of this preparation, suggesting themes beyond the pragmatic and more in line with holistic concepts of process and initiation. It is immediately clear that these considerations are integral to what the session is about and that nothing is too big or too small to be acknowledged and reflected upon. As we head into the relative warmth of the Centre I find myself already to some extent heartened and to every extent welcomed. This is my first conscious moment of 'observing' a community music project and so far, despite the cold, it's all going rather well.

Introduction

The inclusive arts charity *Joy of Sound (JOS)* provides the focus for this article on the use of music as a therapeutic tool within a community setting. The attention here is on how specific methods of communication are used to enhance social bonding, provide opportunities for personal development and contribute to a greater sense of health and well-being. I believe *JOS's* goals, as expressed through attitudes of accessibility, inclusion and equality, may be achieved through engagement of the whole care infrastructure - not exclusively through participants with disabilities - and are also demonstrated through the acknowledgment of unusually powerful moments of silence within improvisatory music sessions.

Background

William Longdon founded *JOS* in 2000 following a chance musical encounter with a man with profound learning difficulties. In order to counter the practical difficulties they faced, William speculated that by adapting the physical nature of the instruments and by using open and flexible music making approaches, a heightened experience of accessibility and communication might be achieved.

This hypothesis proved correct and weekly workshops based on this initial concept followed, as did extensive research into instrument design. 11 years later and *JOS* can boast 13,000+ sessional attendances, the engagement of 800+ volunteers and the design and creation of many bespoke instruments.

Some examples of these instruments are: modified guitars with vibrating acoustic panels, extra handles and protective screens; a wheelchair-presentable broad-keyed marimba; a double zither; a ladybird-coloured carbon-fibre harp; a multi-player interchangeable instrument system and adjustable stand; and a series of customised devices that can be used to hold instruments in variable positions. *JOS* also use computer-based sound modules and electric musical devices.

JOS participants vary widely in age, ethnicity and social background and although wheelchair users make up a percentage of attendees, a broad array of 'special needs' players regularly join support-workers, volunteers, co-facilitators, students and family members for the weekly sessions.

The musicking session

The space inside the Heritage Centre is large and slightly humbling, and my gaze is every so often drawn up into the ribs of the gothic-style church architecture and into the dull winter light (William, although not requested to and subject to necessity, prefers to leave the lights off in order to save the church a hefty bill).

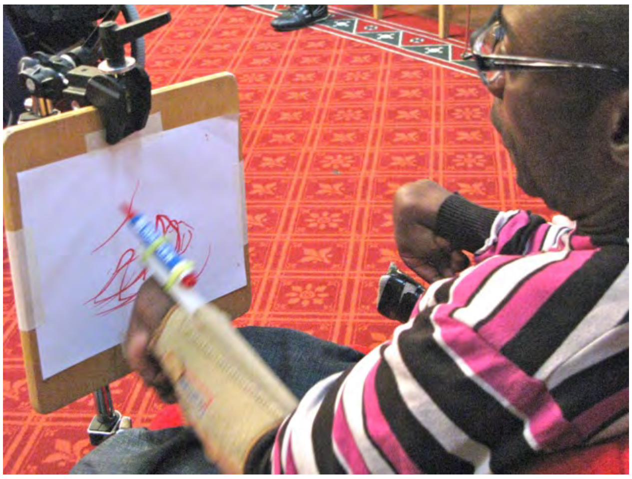
As facilitators arrive, a very gradual momentum of activity gathers pace and conversation follows us around the room.

The first stage of actual music preparation involves the tuning of the instruments themselves. An electric tanpura is used to provide an Eb drone and the pitched instruments are all adjusted to an open tuning with any string aligned to any sympathetic pitch. No drums or percussion are used as they too easily overpower more sensitive instruments in the space.

The first participants to arrive are early and are cheerfully met by William with whom they clearly have a great rapport. Others filter in and a circle of chairs is gradually formed. Instruments are chosen by participants and a few seating alterations are made in order to space facilitators more evenly within the group, which now numbers around 25.

While I am half wondering what is going to happen next and half trying to work out who has 'special needs' and who doesn't (and why am I thinking this should matter?), I notice quite abruptly that we as a group have moved towards a collective focus.

Our musicking starts with the group acknowledging silence, an event so surprisingly charged and delicate that our balance wavers several times before settling just for a moment into a thick layering of hushed concentration and frozen hesitant glances.



A rhythm is introduced by means of a participant-generated musical pulse or gesture, then a melody, a harmony and finally a counter-harmony. In this way a group communicative orchestration begins.

William circles the group identifying melody parts and rhythms present within the clusters of players, then dips into one-on-one exchanges, sometimes mimicking, sometimes coercing different elements of the music to evolve.

The greater group energy drifts in and out of rhythmic alignment as each cluster controls its own micro-dynamic, teeters and sways, follows and leads. Hannah, a bright and wonderfully mischievous young woman with Cerebral Palsy, dances in the centre of the group in her wheelchair.

There is a pace to the playing and an energy. I get the impression that those who don't visibly keep up can't help but be drawn in by the ensemble as both musical sounds and images of dancing bodies rotate around the clusters and into the large room.

After a while William visually gestures for a winding down and we retreat, conventionally or otherwise, back to our silent beginning. This is a further moment of intense concentration, this patient observation perhaps the most challenging to some in the group. Breaths are held. Anticipation is suppressed until a round of applause marks the end.

An appreciation of specific and group contributions is the final stage in the process (which has taken about 20 minutes). After a brief period of chatter and the odd swapping of instruments and places, we start the process again although the energy has lifted a little and eagerness sits in the air.

Following a request for volunteers to initiate the next pre-musicking silence, at least two simultaneous cries of "Me!" and one of, "Let's get drunk!" ring out. Smiles and laughter sandwich our two musicking sessions and Hannah contributes the first musical component - rhythm – through a balletic and silently captivating complete revolution in her motorized wheelchair.

The closure of this second improvisation through directing the group's silence rests on Beni, a quiet and mild-mannered 14 year-old, attending for the first time and probably the youngest in the room. The collective group attention is momentarily fixed and after an achingly deliberate pause, Beni signals for the end. Amid rapturous applause, his mother Beth, also part of the musicking group, immediately rushes over and kisses him bountifully on the cheek.

After this second cycle, with instruments put to one side and the ensemble closing round the three group members in wheelchairs, a third standing vocal improvisation is initiated. The process is the same, although slightly shorter and the hour-long *Joy of Sound* session finishes with a final mutual appreciation of silence and I, as a newcomer, have the honour of calling the end of this week's gathering. As time is evidently a factor, people drift away fairly promptly, although curiously others arrive: it seems this group represents a social cohesion not exclusively based in the music improvisations.

Accessibility, Inclusion, Equality

Returning to my brief of looking at *JOS's* methods and with reference to accessibility, inclusion and equality, several principles became clear to me during my observation.

Although location access and toileting facilities are of course vitally important, it is the focus on how musical instrument design responds to specific physical service user needs that is the very frontline of *JOS's attitude* of accessibility.

William suggests that 85% of access issues with instruments are not to do with the musical workings of the instrument but how they are presented. With this in mind, sweeping leaves from the entrance becomes a poignant statement of intent.

Following on to issues of inclusion, *JOS* demonstrate how freedom of choice is a central consideration. Participants not only choose to come but also choose how they contribute musically, with drifting in and out of the group entirely accepted. This inclusion or exclusion as freedom of choice is not something that exists so readily within the context of everyday life in the care system and it can be seen as this denial of choice that *JOS* attempts to compensate for.

Similarly, although the question of ethics is quite rightly at the forefront of care practice, this can easily form unnecessary barriers and actually increase inequality. Physical touch, the most natural of communicative instincts, is discouraged in many settings, a stance *JOS* pro-actively opposes due to its emphasis on *dis*-ability.

The E*b* open-tuning modal system used also provides a powerful tool to counter inequalities in varied musical abilities within the group. As the whole group is always playing 'in-tune', attention may be more directly focused on more challenging aspects of group musicking such as physical dexterity and playing in time.

But intriguingly it is the silent moments that fall between our most boisterous musickings that most capture my imagination.

Silence

Following Julia Sutton's themes in her studies of silence and music (Sutton 2005), there are two things we can be sure of: firstly and on a physical level, due to our perpetually beating hearts and breath, silence in real terms does not exist. Secondly and on an emotional level, silences are felt to carry a wide range of personal significance and so most certainly should not be seen as 'nothing'.

If we consider silence (or even an *awareness* of silence) as emotionally significant, then certain emotional risks may be attached. But for people who are repeatedly denied the opportunity to take risks of any sort, this may provide a very real way to restore equality.

I would describe the moments of silence as being the most challenging for the group, perhaps where the hardest work is done, and it is far clearer in these instances to see who is 'tuned-in' than when the group is playing.

Beni's mother Beth speaks about his contribution: "everyone felt it because there was complete silence. It was wonderful. I am very proud of him".
Could it be that the interactions between these two states of music and then silence provide the greatest level of accessibility, inclusivity and therefore equality within groups with a wide range of sensory ability? Perhaps it is this that may account for the rich presence and awareness felt in these moments.

Whatever the explanation, William believes they have become "one of the most magical moments" stating also that "you cannot achieve silence without respect"

Engagement of the Whole Care Infrastructure

My final point about *JOS's* methods is the approach of engaging the entire care infrastructure that surrounds the service-users with mental and/or physical health issues.

The relationships between individuals and the environments they inhabit are important and complex and so should not be ignored, least of all when dealing with music and health. This can raise issues though when you consider that potential problems for people with disabilities may just as likely be the care or support structures themselves than any actual physical or mental health problem.

JOS actively tackles this by engaging with four distinct groups: volunteers and co-facilitators; disabled people and people with learning access requirements; the care/support network; and finally, the local community including friends and family. Through the stance of 'if you can't respect yourself then you can't respect others' and a model of 50% altruism and 50% personal development providing an ideal motivation behind each individual involvement, *JOS* show us that *everyone* is a co-learner.

Conclusion

If within these concepts and practices discussed here we may find a greater understanding of the many ways music offers something unique, and there is a will to investigate further into what we do not know, then we may all in some way be grateful to *Joy of Sound*.

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The Joy of Sound website is at www.joyofsound.net

The article is based on a participatory observation research brief to study the use of community music as a therapeutic process and was collaboratively edited with Joy of Sound for this publication.

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Carol Ouvry
Treasurer

‘Turning, listening, moving closer, as you speak, when you dance.’

Arts Therapies for adults with learning disabilities and complex needs

Céline Butté, Geoffery Unkovich and Diana Whelan

The Merton Arts Therapies team collaborates closely with the local community team and mental health team for people with Learning Disabilities. The team’s intent is to encourage creative individual expression through the art forms of Music, Drama, Art and Dance. This therapeutic process supports clients to explore fulfilling and resourceful ways of living their lives.

It is not necessary for clients to have any previous experience or skill in art, drama, dance or music, as it is the process of creative expression and the quality of the therapeutic relationship that are of central importance.

The team’s clinical experience is supported via research, conference presentations and workshops, their participation in special interest groups and the forming of a service-user research network. These all provide valuable learning opportunities which remind the therapists of their familiarity with their Arts modality, and that some clients may not readily engage with the creative arts (Woods & Springham, 2011).

Why the Arts Therapies?

Mencap’s Arts Therapies factsheet (Mencap, 2011) asks the question ‘Why are arts therapies useful for people with a learning disability?’ The answer is that people of any ability have the potential to engage with the Arts Therapies. These therapeutic interventions all provide non-verbal and verbal opportunities for self expression. Difficult emotions and events may be more distressing and cause more problems in the future if they are not expressed; as may often be the case for someone who does not communicate their feelings verbally (Goldbart and Caton, 2010).

This team operates under a shared belief in supporting clients to celebrate their potential, in creative expression for emotional well-being, working with the stigma of a diagnosis, working through interactive communication, engaging with whatever a client brings to each session and inviting spontaneous non-verbal and/or verbal expression. ‘Our intent is for clients and therapists to meet in mutual interaction, engaging in the moment free from inhibitions or pre-conceptions’ (Butté and Unkovich, 2009).

Referrals from key-workers, social workers, psychologists, nurses, doctors, parents, carers, or the Transitions Team come through the Community Team for People with Learning Disabilities. Clients may also self-refer. Reasons for referral may be:

- Coping with loss and change
- Challenging behaviour
- Developing social engagement
- Improving concentration and attentiveness
- Body awareness, mobility, and physical disability
- Working through the impact of trauma
- Sensory processing
- Sustaining motivation
- Building self-esteem
- Specific mental health diagnoses
- Dementia
- Coping with the emotional impact of long-term illnesses

How do I see you? When you move …as you speak…when you dance… wow!

Sam's story shows the power of dance movement therapy with a more able person with learning disabilities. It helps us to understand the second story, about Janine who does fit into our remit of PMLD.

This long term (5 years) one-to-one dance movement psychotherapy support is for 'Sam' who originally presented with many facial tics and head movements that were the initial modes of communication and sharing of movement. Through gradual shared exploration of the facial tics and head movements Sam found her way to try other movement in the room. For example a head tilting action was expanded on by the therapist to include a full torso lean followed by a relaxed arm extension and lift of that arm above the head. This movement raised curiosity in Sam who followed the arm gesture by using a similar but smaller arm movement or by following the arm movement with her eyes. This led Sam to look further around the room and to become interested in other things to do. Sam presented the facial tics as a shared movement warm-up each week and after one year the tics were eventually 'let go' and with this came a more relaxed presentation by her. The movement exploration has provided an opportunity for Sam to let go of the tension and anxiety exhibited in the tics and allowed her to present a more relaxed and less anxious expression in other contexts.

Dance movement psychotherapy has provided an opportunity for all movement expression and non-verbal communication to be explored, amplified, and compassionately shared in a non-judgemental space. The work is always client led and Sam has not been pushed into communicating in ways not of her choice. This long-term therapy has provided time for the slow development of a secure trusting relationship without placing pressure on Sam to speak. There has always been a transparent hope for Sam to speak in order for her to make constructive choices about her life-style possibilities as Sam's dwindling speech has been a long-term concern of her family and professional support network.

During the current therapy the therapist has verbally shared with Sam the frustrations, hopes, and desire for verbal communication experienced in her company. Sam and the therapist have also both spent many hours together in non-verbal creative movement expression. After a recent break of several weeks an emerging theme in the therapy was 'let's try something different'. So each week since then the therapist has pre-arranged the room with different fabrics, percussion instruments, fans, feathers, and/or photographic images. Another aspect of difference the therapist suggested was to be more vigorous and directive with interventions; not to collude with either silence or stillness but to be pro-active in encouraging different movement and sounds. Sam agreed to try this out in future sessions.

The first session of trying something different led to more vigorous and longer dance movement sequences which incorporated a deeper use of breath than usual. Through use of the breath the therapist was reminded of how vital breath is in relation to use of the voice and how shallow Sam breathed. This was shared with Sam who has since been encouraged to inhale and exhale more deeply; as Sam has become more accepting of these directive therapeutic interventions she non-verbally agreed to try speaking more often in sessions. This has been facilitated by the therapist writing down emerging themes and/or questions in the therapy and encouraging Sam to read these aloud. Sam has also written down some words of her own choosing or copied words of the therapist. With developing focus on use of breath before vocalising Sam has become more confident with reading aloud in each session. Some phrases of affirmation read aloud by Sam have been – 'How do I see you? When you move …as you speak…when you dance' and 'fantastic, very good, wow'. The word 'wow' has been particularly expressive because of the exhalation of breath as this is said.

Work with Sam's exploration of sharing the spoken word continues and her pleasure in sharing words is evident in her smile and also in her direct verbal response to questions related to significant people in her life. The improvised movement exploration continues in every session and is the key to the breath which supports the release of the spoken word. Sam has yet to agree to speak with others outside of the therapy space; however this shall continue to be explored in the months to come. When this document was read aloud to her she directly agreed to this 'story' being shared in the wider context.

Ongoing movement exploration with other clients with mild to profound and complex needs focuses on expanding and contracting. This movement action is similar to the physical act of breathing with the lungs, muscles, and ribs expanding and contracting to support the use of breath and thus a potential release of tension in movement expression. For more on this see Butté and Unkovich (2009).

'Sounds of the harp, turning her head and moving closer'

Janine is a woman in her 30s who is partially sighted and does not use words. She rarely joins in any sessions at the day centre, but remains seated on a particular seat in the main hall.

Janine was invited to take part in a therapy group run jointly by a Music Therapist and a Dance Movement Psychotherapist. This group was set up to work with people from across different services within the day centre, and was particularly designed to reach out to people such as Janine who have difficulty engaging with activities taking place around them. Sessions took place in the hall, at the other end of the room from where Janine sits.

During the first few weeks of the group Janine remained seated in her chair and seemed at first to be showing little interest in the group. However there were moments when she turned her head towards the group, and made occasional vocal sounds, or percussive rhythmic knocking on the arm of her chair. She seemed to be showing awareness of the group and letting them know that she was there. On one occasion she even stood up and walked momentarily into the group circle, before turning and leaving again. From time to time one of the therapists would go over to Janine and attune to her slight movements and sounds, inviting her into a dialogue, and occasionally Janine made some small responses. She seemed particularly engaged by the sounds of the harp, turning her head and moving closer as the Music Therapist sat beside her and played. When the Dance Movement psychotherapist sat next to her describing to her what was happening in the room and gently mirroring some of her smaller movements, Janine would respond with soft soothing sounds at times as well as a slight tilt of her head towards the therapist.

Eventually one week Janine stood up and began to move across the room, and when the Music Therapist went over to meet her she took her hand and walked with her to the group space, wandering between the chairs before sitting down. In the following sessions she continued to join the group for much of the time. She spent some time moving around the space with the Dance Movement Psychotherapist, weaving in circling patterns around others and objects, and spent the rest of the time sitting as part of the group circle, apparently listening comfortably to what was going on around her.

This group has now come to an end but Janine is continuing to engage in 1-1 Dance Movement Psychotherapy in the same hall as she prefers to remain in this familiar communal area for the moment.

Janine's exploration continues through therapy work that takes place within an open space; an approach that seems to suit the provision of therapy to clients who present as the most isolated and withdrawn. The combination of Music and Dance Movement Psychotherapy enabled specialist practitioners in creative psychotherapeutic interventions to work with various areas of sensory awareness (for example, tactile and auditory) with a sensitivity that is supporting Janine to gain confidence in taking initiatives and reaching towards others.

Conclusion

These two examples of the Arts Therapies and clients who have a range of complex needs demonstrate the benefits of creative psychotherapeutic expression for emotional well-being. We hope this article has provided the reader with concrete examples of how the Arts Therapies work and some reasons why medium and long-term Arts Therapy for people with profound and multiple learning disabilities can be valuable. The provision of Arts Therapies for adults with learning disabilities in a well structured and established therapies service, integrated into community health teams, can be a successful and valuable source of support for people with profound and complex needs. This Arts Therapies service has developed and grown considerably since its inception, so we are continually grateful to our clients and the multi-disciplinary team for their responsive relationships with us all. Inspired by our clients expression we are constantly reminded that life is for living in diverse and resourceful ways; 'a life that is chosen by them and that involves the unfolding of personal projects embodying their particular commitments' (Ward and Stewart, 2008). We hope that through our future service provision we are able to continue empowering their individual development of personal growth, health and well-being.

'it's a nice refreshing time, peaceful time for me. To talk or discuss, to draw, to think, to communicate my feelings and to communicate my thoughts'
(Quote - Arts Therapies Client)

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The Merton Arts Therapies team web page
http://www.merton.gov.uk/living/care/adultservices/learning-disabilities/arts-therapies-service.htm

Further information

www.apmt.org
The Association of Professional Music Therapists
www.bsmt.org
The British Society for Music Therapy
www.baat.org
The British Association of Art Therapists
www.admp.org.uk
The Association for Dance Movement Psychotherapy UK
www.sesame-institute.org
The Sesame Institute (Drama and Movement Therapy)
www.badth.org.uk
The British Association of Dramatherapists

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US IN A BUS

Linking Lives - communication and connection for people with profound learning disabilities

Us in a Bus – linking lives is an independent, not-for-profit organisation that specialises in working with people who can be 'difficult to reach.' Our aim with each of our clients is the same: we believe that each of us should have the opportunity to discover more about ourselves and to express our emotions and creativity. We use **Intensive Interaction** to find 'ways in' with people who are otherwise very isolated. We learn how people express themselves, find ways of communicating together and establish some common ground. Then we can experiment together, trying out various activities and interactions, encouraging people to develop their sociability and communication abilities – and enjoy themselves in the process.

We deliver a variety of Services, building on the expertise we have gained from 21 years of working with adults and children with profound learning disabilities and complex needs, their families and the professionals supporting them. These include:

Interaction Sessions in people's own homes and in the community working on a 1 to 1 basis or in small groups
Active Support : a coaching programme focused on developing practice of staff within their own workplace
Intensive Interaction Training Workshops concentrating on using Intensive Interaction to strengthen relationships with people with learning disabilities and complex needs. Open courses are delivered in Redhill, Surrey. Dates for 2012 include:

25 April	**5 July**	**4 October**	**Intensive Interaction, an Introduction**
14 June	**4 December**		**Intensive Introduction, Next steps**

Please see **www.usinabus.org.uk** for more details. These workshops can be delivered at your workplace and tailored to your needs. For more details or a booking form please call **01737 764774** or email info@usinabus.org.uk

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SMILE
Sensory Musical Interactive Learning Experience

Celia Chasey

The SMILE project has been running since 2002, originating at Redlands, North Cherwell Daytime Support and has been developed in other day services in Oxfordshire and Warwickshire over the last five years. The project was set up as a result of the 2001 Service Review identifying a need for a stimulating environment for people with complex needs.

SMILE came into being by responding and listening to people's needs and how they wanted their service. It is primarily for adults with complex needs. It is also about having fun! SMILE is set up for people who do not have the same complex communication abilities that most of us find so easy. Most of the people involved will have limited use of language and understanding which will often mean they lead isolated lives.

A total communication approach is used which has made services and support accessible to everyone regardless of their communication ability. Total Communication includes Intensive Interaction, Objects of Reference, symbols, photographs, signing and verbal language. Our priority is to promote communication of any form as well as active two-way learning. The most important resource however will be the passion to believe that people can change and to engage completely and unreservedly with the SMILE philosophy.

SMILE provides a space where interaction and communication occur through the use of sensory stimulation using smell, touch, taste, sound and sight. Sessions are themed seasonally. We use music, rhythm, singing, interactive storytelling, songs and games, each day being structured to suit the people involved and led by them taking into account their likes and dislikes and encouraging experiences taken for granted in everyday life to be shared.

The skill and tools learnt in SMILE by supporters are used throughout the day service and the wider staff teams accessing the project. This enhances staff's understanding and shapes their responses to the people we support in relation to enabling choice making. This in turn helps people to live the lives they choose, however large or small those choices may be.

It has attracted much attention from providers nationally and more recently from an organisation in India with a view to the model being used in a school.

SMILE is a direct access service. Any person can attend with their own support. SMILE sessions can also be set up in other bases, and we are working towards extending SMILE to be used with Elderly people with Dementia in the future.

Experience has shown that SMILE is a project which continually evolves alongside the people who embrace it. Both people with complex needs and their support staff have experienced new ways of interacting. These have helped to overcome challenges and have been successfully used in everyday life. You never change behaviour if you don't challenge it and within SMILE building trust and self- esteem together create empowerment. There are many success stories.

One man who was involved in a sensory story which used a swimming arm band took several weeks to allow it to be pushed up his arm and to feel comfortable about it. His carer had been trying to get him to go to the doctors and they eventually encouraged him into the nurse's room. She was able to put the blood pressure band on his arm. Following this and the trust that had been built over a period of time he became more relaxed about going into hospital buildings and was eventually able to have an ear operation, so he is a much happier man without pain. Consequently his communication has improved greatly since then.

A woman who has been encouraged to stay sitting at the table during SMILE is now able to sit in a restaurant and wait for a meal. She could only go to a drive through restaurant before. She is more relaxed, has a social

Intensive Interaction during a SMILE session at a local campsite!

experience and eats healthier food !

A woman who was unable to go home to her mother and stay the weekend or go on holiday with her parents now does both. She had previously screamed and was unable to stay more than a couple of hours at her parent's house. Her mother wrote in our visitor's book "Our hearts are full of happiness". This woman has attended SMILE for eight years. Using different methods of communication and her own personal story has helped her to feel good about herself and consequently start to interact and feel valued in the group. Sometimes she will intonate lines from the sensory story and gets enormous pleasure from her involvement.

There are other examples, many in fact. Whatever we do we always remember that it is not the activity which is important but the interaction which goes on around it. Every small step is celebrated.

Contact Details

If you feel you would like to set up a SMILE group or would like information about SMILE please contact Celia Chasey allsmiles4smile@gmail.com

SMILE
Sensory Musical
Interactive Learning
Experience

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Auditing the Current Use of Multi Sensory Environments by Students with Profound and Multiple Learning Difficulties

Julia Rhodes

In 2010 I started a new position as Sensory Coordinator at Ravenscliffe High School and Sports College. The school has two multisensory environments (MSEs); both have specialist wiring enabling students to operate equipment via switches. The smaller one is a dark room; the walls and the ceiling are painted black with no natural light. The larger room is a more flexible environment with blackout or whiteout curtains which can divide it into two areas, a double sized waterbed, white padded matting and a bubble tube corner with a mirror to reflect the effect.

This article focuses upon an audit of how the MSEs were being used in school and an overview of the research that suggests how they should be used to enhance the learning and development of students with PMLD.

A Brief History of MSEs

The De Hartenberg Centre in the Netherlands first created a series of sensory rooms in the late 1970s which became known as 'Snoezelen'. 50 years on, there is a competitive MSE industry designing, building and equipping MSEs in educational settings and other facilities for people with PMLD. So, why have MSEs? Pagliano asserts that:

"When a child cannot partake in the multisensory aspects of the natural environments in meaningful ways...The child will require an individual environment which is individually tailored to meet his or her particular needs"

Pagliano (2001) p6.

Longhorn supports this view and states that:

"Without stimulation and an *awakening* of the senses children with profound and multiple learning difficulties would find it almost impossible to make sense of their experiences and begin to learn." (emphasis in original)

Longhorn (1998) p17

Therefore the role of a MSE is to provide multisensory stimuli to match the sensory needs of the user so that they can make purposeful use of their available senses. Three main, although contrastingly different reasons for using a MSE are offered in the literature:

- The Snoezelen philosophy of relaxation, recreation and leisure
- Therapeutic
- Educational

Relaxation, Recreation & Leisure

The Snoezelen philosophy stressed that MSEs give control to the person with the disability with the supporting adult acting as a facilitator, responsively matching the environment to the mood and sensory needs of the individual. Providing suitable leisure opportunities to enhance their quality of life and become fully participating members of society is challenging. Cavet and Mount (1995) recognise MSEs as an appropriate leisure opportunity but emphasise that people with PMLD are dependent on staff to make the environment accessible to them and be sensitive to their sensory thresholds so that they are not over stimulated or exposed to unwanted stimuli for a prolonged period of time.

Therapy

MSEs are claimed to reduce stereotypic or repetitive behaviour. I have observed students who rock continually pause, still and instead focus on a bubble tube or projected image. Similarly I have seen students who habitually suck on their fingers instead reaching out to a fibre-optic tail and explore it with their fingers.

There is evidence from small scale research that the reducing effects on stereotypic or challenging behaviour continue once the individual has left the MSE. Lota and Christian (2009), compared 28 articles of one-to-one Snoezelen interventions with people with intellectual and developmental disabilities to evaluate the therapeutic influence. They concluded that the use of MSEs as a therapeutic approach has some value but significant, rigorous research with large groups of participants is needed to confidently establish this. Pagliano (2001) believes that depression in children with PMLD is more common than is widely acknowledged and a MSE can provide an emotionally supportive environment that enables the child to feel secure and therefore in a position to learn.

Education

Fowler (2008) suggests that MSEs are controllable environments where people can learn to interact with objects and people and therefore develop visual, communication or object engagement skills. The effects that can be created can be a motivator to teach an individual to operate a micro-switch to control the production of the effect and therefore develop awareness of cause and effect which is a significant step towards a learner communicating with other people and developing choice making skills (Goldbart and Caton, 2010). However, teaching the understanding of cause and effect is not easy even when an appropriate reinforcer for the individual has been identified. Most learners with PMLD have difficulty responding to stimuli through different competing sensory channels; e.g. they might not be able to focus on a projected image while music is playing. Therefore, when teaching a class or group of learners with differing needs, teachers may have difficulty adapting the MSE to meet the specific learning environment that each individual may need to learn.

Auditing the use of both sensory rooms at Ravenscliffe School

As part of my role as the Sensory Coordinator I had to audit how the sensory rooms were being used and by whom so I could share good practice and identify areas for development.

The MSEs are booked for use by a teacher or therapist. Scrutiny of the bookings showed that each room was used for less than a third of the time available. They were not used by members of the wider community; on a Saturday morning only a staff member uses it with her disabled daughter who is not yet of school age. These expensive resources were underused despite the literature stressing the importance of MSEs in the learning for students with PMLD. In contrast, the school hydrotherapy pool was used throughout the school day and used by community groups every weekday evening.

In response to a questionnaire I had devised, I found that six teachers delivered lessons in the sensory rooms fewer than three times a year; four did so weekly; and the remaining six either once per month or term. Some teachers teach specific subjects to groups organised according to learners' ability and felt they do not need the MSE environment to deliver their subjects to their students who are at a higher level.

A wide range of reasons were identified for using the MSEs with the most popular being for storytelling. Other popular activities included drama sessions, using the Ultra Violet (UV) lights with fluorescent objects, teaching communication skills, encouraging students to focus and delivering learning through the senses.

Teachers' opinions on the purpose of a MSE were diverse; learning and relaxation were both mentioned and a focus on building a single skill. Interviews with the school's Visual Impairment Adviser and Speech and Language Therapist revealed that they used the MSEs as a quieter environment for assessment of a student's specific skills such as visual tracking skills and also to monitor the student's attention on an activity.

Recommendations for using the sensory rooms in the future

From the evidence in the literature and from my audit I recommended that good practice would be:

- Using the MSEs to create atmospheres for storytelling or drama in mixed ability groups. Examples of this good practice could be filmed and available to new staff who feel less confident in this area.
- Using the UV lighting with a variety of fluorescent materials to motivate students across different abilities and curriculum areas.
- Making the MSEs available for individual assessment and multi agency assessment involving teachers.

Much of research on MSEs that I have identified is over 10 years old; many of these authors identified the need for significant and rigorous research into the use of MSEs. There is a dearth of up-to-date research and what I have read has shown no clear conclusions or recommendations on the use of MSEs. With the lack of a contemporary evidence base in the use of MSEs with people with PMLD, good practice will be dependent on reflective practitioners. Therefore, during this academic year I have begun taking small groups of students with similar needs into a MSE on a weekly basis to work on learning targets. This has allowed some comparison with how they progress with these same targets in the ordinary classroom environment.

My work with a range of students with PMLD is starting to develop a clearer picture of the benefits of MSE use and how to match activities and equipment to best meet the needs of the learners. However, as always, it is very difficult to generalise as people with PMLD are so diverse their needs and requirements in an MSE are as unique as they are!

When working on communication skills, creating a calming environment through music, scent and softer lighting such as the bubble tubes has helped individuals with stereotypic behaviours to direct their attentions to a person and has lead to more successful Intensive Interaction sessions. Alternatively for some mobile students the padding of the MSE may remind them of children's 'Play Gyms' and they have difficulty concentrating on communication or switch based ICT skills and I find the more formal environment of a classroom a better place to encourage them to focus on these activities.

The ability to blackout in an MSE does provide a key environment to work on visual skills. This has been much more successful without background music where students have been positioned against an uncluttered background and offered items such as the 'magical' fibre optics (which most of us regardless of age and ability are drawn to look at) and given time to focus upon and track. One student working at very early developmental levels has shown fleeting awareness of the projected lights but has had more success at focusing on bright bold items when in natural daylight so a balance of activities offered in both environments is required to encourage her visual skills.

Under ultraviolet light fluorescent colours become 30 times as bright as ordinary colours (Cartwright and Wind-Cowie, 2005). Fluorescent items are available in a variety of materials from plastics and fabrics to paints and bubbles. For most students this brightness has encouraged them to reach and explore a diverse range of materials, although for others, including those with cataracts (Hirstwood and Gray, 1995), this brightness can be uncomfortable. One student who rarely uses his visual skills has been able to show us that he dislikes this brightness by consistently closing his eyes and pushing fluorescent items away so is offered different opportunities to use his close visual skills.

Thanks to a legacy we are updating and reequipping the large MSE this year. Looking at students' learning has informed us that the design has to be even more flexible so that the environment can be finer tuned to students' individual needs. I hope that the increased flexibility will be adaptable to different teaching styles so that in the future it will enable the MSEs to have a greater role in the delivery of lessons across all curriculum areas.

What has become increasingly obvious to me throughout my research is that the most important piece of equipment in an MSE is in fact YOU the practitioner!

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Living in the Present

Jill Goodwin

When conceptual thinking is profoundly impaired, life cannot be lived in dreams, wishes, worries and hopes……it is lived in the present.

In the context of 'Life is for Living', the theme of this journal, I am writing this article because I wanted to share how the learnings I have made in the course of my work with people who have PMLDs have enhanced and enriched my life. I write as an artist and teacher who has worked in various capacities over recent years with young people (ages 2 – 19 years) who have PMLDs.

If we could all spend time together in this moment, undistracted by thoughts, there is such opportunity for authentic communication and life-affirming contact.

The above statement came to me recently and stayed in my mind. It expresses how I view the process of engaging and communicating with someone with profound and multiple learning disabilities and why (as well as hopefully improving the quality of life for that individual), I stand to gain so much from these interactions. In those (sometimes rare) moments when I manage to be 'fully present' with a child or young adult, if they choose to engage and share themselves with me in some way, I feel enormously privileged and re-invigorated. They give a gift.

It is in my capacity as a teacher, that I am sadly most at risk of never seeing these moments. The management of a busy classroom with all that that entails, including the responsibility of important healthcare needs, is when my mind is most prone to become full of busy-ness, logistical decisions and general stress………and yet these are also the times when my statement becomes most pertinent. An entire week of stressful work can be made totally worthwhile by just five minutes of engaged and playful contact between myself and one pupil.

At Rosewood school in Southampton, the staff team have worked hard to address the issue of how to utilise all opportunities for meaningful engagement by examining the curriculum and embracing all routine care procedures as part of the learning environment on offer. This has helped to reduce the tension for us as educators from feeling that 'lessons' are interrupted by personal care, physio and positioning interventions, etc. and to recognise that all of these routine 'procedures' are rich opportunities for communication and learning. In this way, the school day is not separated into "attending to care needs'"(so that learners are comfortable and able to utilise learning opportunities) and "lessons", since now these care procedures are all recognised as an essential part of the learning environment.

As an artist I feel especially privileged in my work, because I can draw upon additional ways to elicit engagement and interest from learners with profound intellectual impairment. I am regularly moved, delighted and inspired by a child's desire and ability to play (with a sense of humour!), even when facing the most extreme barriers and difficulties, including pain and severely restricted movement.

I particularly like to use music and singing, as well as 'immersive environments' when possible in my work. My use of environments has taught me the power of atmosphere to bring about a heightened attention and quality of contact between people, and in this way my work can enhance engagement in a whole group of staff and students. If learners and their partners are brought into a space that has a magical or in some way arresting atmosphere, the likelihood of us all being 'in the moment' is drastically increased. Staff become highly attentive to their partners and so the chances of them sensitively receiving and responding to communications from pre-verbal youngsters are improved.

At Rosewood school, Intensive Interaction and Affective Communication Assessment (ACA) are integral to all areas of the curriculum so as to support staff in their efforts to understand how children are communicating and what those communications may mean. The structure and framework of these tools has enabled me to strengthen my intuitive approach with something based in more solid research. Ultimately though, it is the human ability to attend sensitively to another being, to be open, receptive and ready to respond intuitively to their communications that is the crucial component. This willingness to put all other distractions aside and devote oneself entirely to that moment with that individual, is an investment which I find reaps huge rewards.

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FUTURE FOCUS: Family and friends

What *really matters* in your life? What *makes the difference* - to the quality and enjoyment you experience? These questions usually bring us to a common response – that *people* and *relationships* are 'key'.

Sharing your life with family and friends for the majority of us is seen as *the* most important and the most satisfying aspect of life. For some people, the concept of 'family' or 'friends' might not be the conventional one. In their lives, other people take on a very significant role in their lives; one that is sensitive and responsive to that individual – going above & beyond the 'job specification' of professional, paid or supporter role.

At the heart of our identity and safety are the relationships we have with family and friends. Families provide continuity of knowledge and shared histories that support people in the present and help them plan for the future. Their commitment and involvement is **lifelong...'**and beyond'.

'And beyond...', because despite the many uplifting, remarkable and inspiring people families meet [hopefully!] they also know the real dangers their loved ones face. Not just from obvious abuse, but from an insidious indifference and isolation, punctured by the occasional bout of sentimentality. So often such consequences are unintentional – but due simply because people *don't know*. This might be a lack of training or more simply about not sharing some essential bit of information. Professionals and paid staff inevitably come and go in the lives of people with PMLD – families and friends are in it for the long-run...*for life*!

For people with PMLD who need support with all aspects of their life, family and friends are critical - for giving care, for getting the care people need when family cannot give it, and for safeguarding against abuse and loneliness. They champion their loved one and exchange joy and friendship. Most families we know reward each other by giving and sharing joy, delight and hope.

People who have family and friends involved in their lives have better outcomes and this is recognised in law. The Mental Capacity Act expects those interested in a person's welfare to be consulted when important decisions are being made or planned for and this includes family. Often family and friends will be the persons' advocate. They support their loved one to make decisions or make decisions in their best interest if they reasonably believe the person lacks capacity. If a person doesn't have family or friends to help them advocate in situations where they need to make such decisions they have to have an Independent Mental Capacity Advocate.

It is often small but significant details that form the building blocks of someone's health and wellbeing - *how* a person has their face washed or their teeth cleaned may be very significant for any number of reasons. Familiarity offers the chance for an individual to develop anticipation and then a greater involvement in their daily activities or care. Parents and family carers so often hold the key to having a crucial, holistic view of someone; it draws together tiny but significant details [often unknown to others] that can make a big difference. Many such details are often viewed in isolation without the 'family's insight' of how they may relate to other aspects of someone's well-being - for example, constipation and increase in seizures; using a roll-on deodorant because a aerosol is 'too much' for someone who experiences sensory sensitivities of touch, or using the right soap to prevent skin irritation – which can be excruciating if you cannot scratch an itch! These details offer clues and an insight that at one level may impact on daily quality of life, but may also help identify or even prevent a sudden or unexpected deterioration in health. A change in shampoo may trigger hair matting, hair loss, and end in sores on the back of a person's head. The precise consistency of food or tasters may determine whether someone eats or tastes safely as well as offering the optimum chance of nutrition.

Family and friends are of course a source of great joy and comfort at many levels. Whether this is through the familiarity of day to day routines or simply sharing a space to *just chill* or *hang-out* together- or, by sharing the excitement, spontaneity and novelty of celebrations, special events or holidays.

If you have experiences, ideas or comments to share we would love to hear from you. We welcome articles from all perspectives - whether you are a family member or a 'friend'

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Jim Mansell: Architect of learning disability policy

Many people across the learning disability sector, families and people with a learning disability are mourning the loss of a very inspirational man- Professor Jim Mansell, who dedicated a lifetime to improving the lives of people with a learning disability.

Jim began his career in the world of learning disability in 1970, while studying at Cardiff University. After volunteering to take a group of children with a learning disability to the local cinema, he was appalled to discover the poor living conditions and lack of basic freedoms at the long-stay hospital they lived in. Not many undergraduates would have taken the action Jim did, making an appointment with the director of the hospital and telling him to close it down!

Recalling the radical work that Jim did as a student in Cardiff with the young people from Ely Hospital, Rob Ashdown, Head Teacher spent a year living in the CUSS group home Jim set up in Cardiff in the mid-70s, commented that 'At the time, as a naive student, I really did not appreciate the radical nature of what Jim was trying to achieve. The fact that the project was so successful says a lot about his tenacity and farsightedness. And his hair was longer than mine!'

Jim went on to fight for the closure of long-stay hospitals and became England's leading authority on the needs of people with a learning disability who display challenging behaviour. In 1983, he founded the University of Kent's Tizard Centre – recognised as one of the world's leading research and study centres for learning disability. Beverley Dawkins, Mencap's national officer for profound and multiple learning disabilities, studied her MA with Jim. 'Jim had a way of directing you to the heart of an issue, to construct an argument for change, to make it count by taking it to the right people and to then to keep on making it until people eventually give in! I have stuck to that advice ever since'.

As an adviser to the government, Jim led an extensive programme of consultancy and research that focused on improving the lives of people with a learning disability. His influential report into services for people with a learning disability and challenging behaviour – known simply as the 'Mansell Report' – was published in 1993 and revised in 2007 to support the 'Valuing People' strategy.

In 2010, he wrote the first government commissioned report, 'Raising our sights', into planning and delivering services for people with profound and multiple learning disabilities (PMLD).

Last year, Mansell appeared on the BBC's Panorama programme, to condemn the abuse that took place at Winterbourne View residential hospital near Bristol. Along with former national director for learning disabilities Anne Williams and Mencap chief executive Mark Goldring, Mansell formed an advisory group to help the Department of Health form its response to the abuse.

This January, despite very poor health, Mansell visited Buckingham Palace where he was awarded a CBE in the New Year Honours List for his services to people with a learning disability. Jim made an exceptional contribution to the lives of people with a learning disability. The work he has done, focusing on people with the most complex needs, such as those with profound and multiple learning disabilities and those with behaviour which challenges, has helped ensure that some of the most marginalised people in society are at the forefront of our thinking.

Beverley Dawkins
National Officer for Profound and Multiple Learning Disability Mencap National Centre

Picture from: http://www.challengingbehaviour.org.uk

PMLD Network Forum
A Digest of Discussions
December 2011 to March 2012

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.

Smart wheelchairs

Someone who is writing a guide on Wheelchairs for Mencap - which will be one of a series of 'local how to guides' they are writing to help local areas implement the recommendations from Raising our sights - said they were looking for a case study of an adult with PMLD who has a 'Smart wheelchair'. She said she has examples of people who have received complex seating, but that she is having difficulty finding anyone with PMLD who has a 'Smart wheelchair'. By this, she said she means:

- a wheelchair that allows for environmental controls or
- one that can be powered independently on a tracking system, or has other 'smart electronic features' that give some independence of movement or
- one that can be used to change position from sitting to standing etc.

She said there are examples of other people with this type of wheelchair but so far she has drawn a blank for people with PMLD.

The responses showed that there is lots of confusion about what Smart wheelchairs are. Those who have had the opportunity of using them with people with PMLD speak of the benefits, whereas other people are in the dark about what they are exactly and/or how someone with PMLD could use and benefit from one. Responses included:

- 'We have a Smart chair at our school which we have used with pupils of various ages. It can be switch operated and follows a 'line' on the floor.'
- 'I am not at all surprised that you have not come across adults with PMLD using smart wheelchairs - unless the definition of PMLD has suddenly changed dramatically, there is no way that a person with PMLD would have the cognitive ability to operate such a device. '
- 'This illustrates the problem of categories which are not clear, and may therefore not always be helpful. We also have a 'Smart' chair at our school which we have used with pupils of various ages and various cognitive abilities. It can be switch operated and follows a 'line' on the floor, this gives wonderful cause and effect experiences/sensations. Likewise we also have a Smart chair at school (ie a motorised platform, which a student's own wheelchair can be put on to). Students then operate the chair with the use of the switch. The main purposes of this device is to provide students with PMLD another opportunity develop contingency responding and contingency awareness, as well as experience a degree of independent motion.'
- 'I've never heard of Smart wheelchairs. I think that because of the complex needs of someone with PMLD, no matter what parents ask for the expectation is that that person can't operate anything so there's no funding made available to provide a smart wheelchair or anything else that's smart.
  I'm all for smart stuff - but I wish the forward thinking and available funding were also available!'
- 'I have been really pleased to see reports from schools of Smart wheelchairs being used with students with PMLD. I wonder if the confusion relates more to a communication gap between schools and parents. Parents may not always be kept informed about work on cause and effect/ contingency responding and how technology makes it possible for their son or daughter with profound disabilities to engage in and benefit from this work. Our work on communication strategies (www.mencap.org.uk/all-about-learning-disability/information-professionals/communication) suggested that parents were not routinely being kept aware of communication interventions being used with their sons and daughter.' - Professor Juliet Goldbart, Manchester Metropolitan University.
- 'Ummm...communication interventions.....that would require some sort of input from a communication specialist such as a SALT presumably - my son hasn't seen one in three years despite it being in his statement. For him to use a Smart wheelchair would require him to learn that a switch use has an effect. Some PMLD children are functioning on a very low cognitive level that isn't compatible with Smart wheelchair use.'

Withdrawal of vital support

Someone who said they have been a long-time contributor to the PMLD network said they now urgently need readers' advice and support.

They said they have a son in his forties with PMLD who cannot speak and has severe epilepsy. They said that for the past 16 years he has lived happily in his own purpose-built bungalow with 1:1 support provided by a domiciliary care provider. He lives in one county but is but is currently funded by social services in another county with a 25% contribution from Continuing Healthcare. There has been a long-running attempt to move funding responsibility to the county he now lives in. They said there is now a stalemate situation and the provider has served notice of termination of the service from next month because they can no longer provide a 'safe' service with the funding they currently receive.

They said that this leaves their highly vulnerable son without any provision and leaves them as a family, with an impossible task; either to find a new, reliable and understanding support provider - a really difficult task in the county he is living in - or to commence battle with the statutory bodies to increase his care package funding. And all this in two months. They said the family is devastated by this action, and their only consolation is that their son will have no understanding of these events. They said his happy life will be totally destroyed when he is forced to cope with a new team of inexperienced, poorly-paid support workers, none of whom will have any knowledge of him and his ways of communication.

Responses included:

- 'What a horrendous situation. I am sure you have thought if these things, but I do think it is worth trying to get your local councillors and MP on your side and active. Your local paper might be interested - which would stimulate some action from the councillors and MP.'
- 'We had exactly the same a year ago with our son who had an identical situation as your son. We fought hard and involved our local MP who was absolutely brilliant, even coming with us to Social Services at our Council Offices…You will have to be prepared to possibly use the media as a last resort. In the end they have left us alone and carried on the funding but we realise we will always have to be aware that this will probably happen again but as a family we will fight to the end for our son and I am sure you will do the same.
  Please do not give up.'
- 'In your shoes I would request in writing for a full review of his assessed needs (if that has not already happened in the last year) This will halt any action until it is completed.'
- A couple of people suggested contacting a solicitor skilled in this area, who could tell them their son's legal rights and all the avenues that could be used. For example, Belinda Schwher www.careandhealthlaw.com or Luke Clements www.lukeclements.co.uk/
- 'Is there a robust and effective advocacy service locally?'
- 'In light of the scandal at Winterbourne View it may be worth contacting the challenging behaviour foundation where you will find allies and information.'
- The bottom line here is that your son's needs have been assessed and the support he is given is the result of that assessment. This is a legal entitlement and can only be changed by a re-assessment, which itself can be challenged.
- In negotiation around complex issues it can be helpful to at first step back from the situation and carefully consider the possible outcomes from a 'what is in it for me' perspective - looking for a 'win-win' solution. Can you shower the current commissioner and provider with appreciation and praise? You say that he has lived happily for 16 years - can you reflect back the huge practical and emotional benefits to the current arrangement ? I know these suggestions sound contrary to what you will understandably be feeling but we tend to treat each other well and come to more humane conclusions when we are appreciated.
- 'This is appalling and not lawful. Locate a good advocate and a solicitor in your area that deals with care issues. They should be able to advise you quite quickly if action can be taken on behalf of your son.'

PMLD and reading

I am new to PMLD and have been asked to create an interactive wall display to promote early reading skills for PMLD students P1- P4.

Does anyone have any creative ideas please? I am hoping to create something that the pupils can assess independently as they are all physically able. The pupils are 13 - 16 years old and I am struggling as to what reading actually is to PMLD students? I have been using objects of reference/ matching photographs to objects/ recognising photographs of themselves/ large magnetic letters to explore on a board on the wall etc but not sure that I am along the right lines. If anyone has any suggestions for me it'd be much appreciated.

Replies included:

- I would question the appropriateness of such a display as they are a long way developmentally from even early reading skills unless you are going to argue that exploratory and sensory play are early reading skills. So you are on the right lines attaching objects - how about having matching pairs of objects that can be linked together - using familiar items / things that engage individual pupils or the objects could be attached to a line so they can move along or long and short pieces of elastic to attach them which gives an interesting effect when you let go!

- Someone suggested looking at the Maths extra website for some pointers http://www.mathsextra.com/
- This is not really the practical information you were asking for, but there is some research on what literacy means for pupils with PMLD. The references are:
  - ♦ Lacey, P., Layton, L., Miller, C., Goldbart, J. & Lawson H. (2007). What is literacy for students with severe learning difficulties? Exploring conventional and inclusive literacy Journal of Research in Special Educational Needs 7 (3), 149–160.
  - ♦ Lawson, H., Layton, L., Goldbart, J., Lacey, P. & Miller, C. (2012). Conceptualisations of literacy and literacy practices for children with severe learning difficulties. Literacy Early view DOI: 10.1111/j.1741-4369.2011.00603.x They suggested contacting one of the authors by email if you have problems getting hold of the papers.
- ‘Developmentally where are the children’s learning levels? Have a look at the Wolfson scales (A Comparison of P Levels and Developmental Assessment Framework used to assess PMLD and SLD - Great Ormond Street.)They show what comparative level the children are operating at.’
- ‘What exactly do these children need in terms of pre –reading skills? Surely we should focus on early communication and early cognitive development. Have a look at our assessment (ImPACTS). We focus on development of very early skills in Communication, Cognition, Environmental Control Technology, Physical Skills, and Personal Social Emotional Well Being. Sensory trails/ mobiles/ wall boards are readily available’ – Headteacher, Rosewood School.
- ‘I would suggest looking at the site run by Richard Hirstwood and Flo Longhorn for ideas and inspiration - www.multi-sensory-room.co.uk/index.html
  This is also a link to sensory story ideas by Richard Hirstwood - www.multi-sensoryroom.co.uk/page76/page30/files/Sensory%20Stories.pdf
  I would also strongly recommend going on one of their courses, if you can, as they are truly inspirational and you will come away buzzing with ideas.’
- In terms of early reading skills, Penny Lacey's research is invaluable. It depends entirely how you define reading. Our education system and the Government think of reading as decoding written text. However (see a wonderful book by Alberto Manguel) reading can be conceptualised far more broadly than this. Many written languages employ pictographic representations and as a society we are moving away from text towards more pictographic cues in media and in the environment. We "read" the stars, footprints and tracks…it's about how we interpret marks and signs in our environment. For kids using AAC systems such as pictures and symbols, they effectively have to learn to "read" simultaneously with communication. The same might be said for young people with PMLD who have to learn the correspondences between objects and photos and the things they denote. So at this stage it is not a matter of pre-reading or communication, communication can involve "reading" and indeed "writing" in a broadest sense.’
- ‘At Bag Books we're all about PMLD and reading. If you have a look at the early P Level descriptions you'll see it's all about raising levels of response and interaction with a range of stimuli. If you have any of our storypacks, have a look through for some inspiration. I would say you could just stick up all the pages from one of our stories, but they're not really intended to be used unsupervised so they may get damaged or there could be some health and safety issues with that. What I'd do is think of a very simple story, just a few lines long, and for each line put up some sort of sensory stimulus. It could be something to smell or touch, something very visually stimulating, or something that makes a sound. Try to use as many of the senses as possible.’
- ‘When I was working in a day centre I developed books with folk with people with PMLD that were non-text based - they were fabric or shiny collages - the gold book, the soft book, the rough book. Handling these and going through the pages was in my view ‘reading’. You might like to try this, it's great fun.’
- ‘I think all these imaginative multi-sensory approaches to communication are great in their own right - but why do we need to say they are early reading skills? I think this is stretching a definition way too far, and I'm not sure for whose benefit.’
- ‘The truth is they are early everything skills, not just reading skills. Children (and adults) with PMLD are operating at a level where they are learning to respond to, explore and interact with the world around them. These are basic building blocks from which all further learning can be/is built. If you're not yet at a level where you can show a meaningful response to something, for example a sound or

smell, then you've got a very long way to go before you can respond to written language.'

- 'The P Levels that are used in schools to measure progress make very interesting reading at the lower levels normally associated with PMLD. Levels 1i-3ii are almost identical for every subject in terms of the skills they are expected to show, and the only differences are the examples used. So basically, regardless of the subject being taught, the pupil needs to be working on the same set of skills. It's up to the teacher to find a way of connecting learning these skills with the theme of the lesson. In art this may be exploring paint, brushes etc, whereas in English it may be exploring items associated with a story or topic that's being covered.'

MOVE

We are thinking of introducing the 'MOVE' intervention to our special school and we are searching for experiences of other facilities which have invested in the intervention.

Replies included:

- 'We've been using MOVE for years at our school, and find it an excellent approach for meeting the children's movement education needs.'
- 'We have been using MOVE in our school for over 10 years and it provides an invaluable framework for teaching functional sitting, standing and walking skills and allows you to measure and record even very small amounts of progress using the measuring and removing the prompts steps.'
- 'We are now a regional centre of excellence and are happy to receive visitors who would like to see MOVE in action we are based in Leeds there are other centres around the country look on the website to see if there is one near you.'
- 'MOVE has made a real difference to the lives of our students but I know it was hard work to get to where we are now with it. Worth it though. Has someone from your school been on the MOVE course yet? You could speak to the MOVE office for advice, they are really helpful and friendly. They can advise you where your nearest MOVE centre of excellence is and you can visit. Where is your school?'

Some of the key resources and publications shared on the forum:

- Top Tips for supporting and meeting the needs of people with Profound and Multiple Learning Disabilities (PMLD)
- http://www.choiceforum.org/docs/em.pdf
- · SCIE is developing a new website to help people to make choices about care. They have published a holding page for Find Me Good Care which will be launched later this summer. The site will provide information about care and support for all adults, including regulated and unregulated services. See www.findmegoodcare.co.uk
- · SCIE have produced 2 guides about protecting adults at risk:
    - ♦ The first guide shows how safeguarding in care homes should be central to the commissioning process: www.scie.org.uk/publications/guides/guide45/
    - ♦ The second guide aims to identify issues that commonly lead to safeguarding referrals from care homes: http://www.scie.org.uk/publications/guides/guide46/
- Raising a concern with CQC: A quick guide for health and care staff about whistleblowing http://www.cqc.org.uk/sites/default/files/media/documents/20120117_whistleblowing_quick_guide_final.pdf

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

Visit the PMLD Network website at www.pmldnetwork.org

IN THE NEWS

Lobbying to change social care

More than 1,000 people attended a mass lobby on 6th March to tell the government that the social care system in England is in crisis. The End The Care Crisis lobby was organised by the Care and Support Alliance – a consortium of over 50 organisations that represent older and disabled people. The campaigners included people with a learning or physical disability, older people and those who represent and support them.

With the government expected to publish its white paper on social care reform in April, the lobby was organised to remind all 650 MPs that they still have the chance to change the social care system for the better. Throughout the day, many of the lobbyists met with their MPs to share their stories of using social care services.

Yvonne Lee, head of campaigns and community at Harrow Mencap, said: “Unless something’s done about social care funding, people are going to need emergency care, which will cost a lot more. We’re really worried about people losing their services, which will lead to them losing their independence. We’re seeing, on a daily basis, people being given reviews – they always lose their services.”

Simon Gilespie, chief executive of the MS Society and chair of the Care and Support Alliance, said that the lobby has been an outstanding success: “There are lots and lots of people putting their personal stories to their MPs – we think we’re accessing at least two-thirds of the MPs who have a constituency, so that’s really significant,” he said. “It’s empowering and motivating that so many people want to pass on the message that the system’s not working, and unless it’s sorted out quickly, it’s not going to work for the next few decades.”

CQC's inspection of learning disability services post-Winterbourne

The CQC has been carrying out focused inspections of 150 services for people with a learning disability, following the abuse scandal at the privately-run Winterbourne View residential hospital near Bristol. The abuse was highlighted in a BBC Panorama programme which aired earlier this year.

The Care Quality Commission (CQC) has now completed their focused inspections of 150 services for people with learning disabilities.   The reports from these inspections are being published in batches. To date 86 inspection reports have been published. These reports can be found at www.cqc.org.uk/LDReports?latest

The inspection programme has been checking against 2 essential standards: one is around care and welfare and one is on safeguarding adults from abuse. The inspection reports to date show that many services are not fully compliant with these essential standards.

In a joint response to one of the batches of inspection reports, Learning disability charities Mencap and The Challenging Behaviour Foundation said:

"These latest CQC reports again reveal serious concerns about the care people with a learning disability are receiving in specialist assessment units.

These post-Winterbourne reviews are providing a strong justification for moving away from institutional care towards developing local services, where people are less likely to be out of sight and out of mind, It is crucial the Government ensures these changes are made to reduce the likelihood of the abuses seen at Winterbourne View happening again."

The CQC will be publishing a national report on the findings from their learning disability inspection programme. This will feed into the wider review that the Department of Health is doing on Winterbourne View, which will be published in due course.

Support for hate crime campaign from Metropolitan Police

In February the Metropolitan Police Service signed up to Mencap's 'Stand by me' police promise. Mencap launched the 'Stand by me' campaign during Learning Disability Week 2011 to raise awareness of learning disability hate crime and put a stop to it. As many as 9 out of 10 people with a learning disability are verbally harassed or exposed to violence due to their disability.

The 'Stand by me' police promise is ten pledges that will help to ensure people with a learning disability can live their lives free from the fear of hate crime. These include holding regular beat meetings and ensuring they are open to disabled people, challenging discriminatory attitudes among fellow officers, and involving families, carers and support staff of disabled people.

So far, 30 of the UK's 43 police services have signed up to the police promise.

Metropolitan Police Commander Steve Rodhouse said: "The Met is committed to tackling all forms of hate crime and recognises the significant impact disability related harassment and crime has on communities. We know under reporting of hate crime is a significant issue and we are resolutely committed to tackling all forms and categories of these offences."

This year, Learning Disability Week will take place from Monday 18 to Sunday 24 June and will again focus on hate crime.

Benefit changes ‘harmful’ to disabled people

New report says cuts to benefits and services could leave disabled people unable to live independently. The Joint Committee on Human Rights (JCHR) published its report on the implementation of the right of disabled people to independent living at the beginning of March.

The JCHR is made up of 12 members, from the House of Commons and the House of Lords. It is charged with considering human rights issues in the UK.

Written in the context of the UN Convention on the Rights of Persons with Disabilities, ‘Implementation of the Right of Disabled People to Independent Living’ raises a number of significant human rights issues. They include the need for freestanding legislation to protect the right to independent living in UK law and the effect of current reforms to benefits and services on the ability of disabled people to enjoy independent living.

The right to independent living is not set out in UK law. In the report, the committee argues that the government should immediately assess the need for, and feasibility of, legislation to cover this.

The committee also found that reforms to benefits and services risk leaving disabled people without the support they need to live independently. The report says that ‘the range of reforms proposed to housing benefit, Disability Living Allowance, the Independent Living Fund, and changes to eligibility criteria risk interacting in a particularly harmful way for disabled people’.

DLA victory confirmed

In December, the Government announced that the mobility component of Disability Living Allowance would not be cut for thousands of disabled people

The statement also confirmed that the mobility component will continue to be paid under the Personal Independence Payment, which is set to replace Disability Living Allowance (DLA).

Campaigners celebrated following the news. The mobility component allows disabled people who live in residential care homes to get out independently, by allowing them to meet some of the extra costs of accessing suitable transport or to purchase appropriate mobility aids.

The government’s decision was partly in response to the findings of the Low Review, an independent review carried out by Lord Low of Dalston at the request of Mencap and Leonard Cheshire Disability. The review, which gathered more than 800 submissions, found no evidence to support the government’s claim that funding for the DLA mobility component is duplicated by local authorities.

The statement from the DWP said: “We have now gathered and reviewed further evidence, including the helpful contribution provided by Lord Low’s review… there was insufficient evidence of overlaps in funding provision to justify the withdrawal of the mobility component.”

74 deaths and counting

Mencap is calling on the Government to make the NHS safe for people with a learning disability, following the publication, in February, of a new report ‘Death by indifference: 74 deaths and counting’, which finds continued institutional discrimination in the NHS.

The new report looks at what progress has been made since the publication of Mencap’s original ‘Death by indifference’ report in 2007.

It confirms that, although some positive steps have been taken in the NHS, many health professionals are still failing to provide adequate care to people with a learning disability. The report highlights the deaths of 74 people with a learning disability in NHS care over the last ten years – highlighted in an article in The Guardian in January – which Mencap believes are a direct result of institutional discrimination and could have been avoided.

The report uncovers common errors made by healthcare professionals. These include failure to abide by disability discrimination law, ignoring crucial advice from families and failing to meet even basic care needs. Mencap believes that this is underpinned by an assumption by some healthcare professionals that people with a learning disability are not worth treating.

The report also shows there has been no systematic monitoring by the Department of Health to ensure that the health needs of people with a learning disability are being met.

For more information see: http://www.mencap.org.uk/campaigns/take-action/death-indifference

New resource on the Mental Capacity Act 2005 for family carers of people with PMLD – with a focus on healthcare decisions

Mencap has produced a practical resource for families and carers about the Mental Capacity Act 2005.

The aim of the resource is to:

- enable their involvement in best-interests decision-making
- equip them with the information they need about the Mental Capacity Act
- help them understand how the act impacts on a range of decisions.

It is aimed primarily at families and carers of people with profound and multiple learning disabilities (PMLD).

The resource focuses particularly on securing the best outcomes for people with PMLD in dealing with healthcare services. We know from our health campaigning work that family carers and people with PMLD are not always involved and listened to when decisions about healthcare are made. This resource equips families to know their rights and gives practical suggestions of how they can ensure that they and their family member who has PMLD are involved in decisions.

The resource includes film clips of families telling their own stories - positive and negative - of their experiences of healthcare. The resource has been funded by SCIE (Social Care Institute for Excellence), with families providing invaluable guidance through an advisory group.

Download the resource www.mencap.org.uk/all-about-learning-disability/health/mental-capacity-act

You can request a free copy of the resource on a CD-Rom at publications@mencap.org.uk

Jean Willson OBE – family carer *and* champion!

Jean will be a familiar face to many readers- not least from featuring with her daughter Victoria, on our front cover last year! In December, just before her 70th birthday, she was awarded the OBE for her continued work for family carers and people with learning disabilities.

She acts as Champion for people with profound intellectual and multiple disabilities in Islington on the Partnership Board, and sits on the Health and Housing Working Groups. Nationally, Jean has been a member of government groups working on behalf of people with learning disabilities and their family carers. She currently represents the London Region Family Carers at the National Valuing Families Forum, which advises government. Jean is also a trustee of Centre 404 – a charity supporting people with learning disabilities and their families. She has been a member of Centre 404 for 40 years!

Jean has a special interest in health and housing for people with learning disabilities. She has an adult daughter with multiple disabilities and twenty years ago, along with another parent, set up the first supported housing in England for their daughters

This isn't the first time Jean's efforts have been recognised - in 2010, she was one of four hundred women who were named *Women of the Year* - for making an outstanding contribution to their fields. In October last year, Jean was filmed talking about her work with family carers at Centre 404...for tv's 'Secret Millionaire'! Congratulations Jean!
For more information : http://www.centre404.org.uk

RESOURCE

The Whole Shabang! Volume One

A treasure chest of educational gems – a must for any creative learning space!

Shabang Theatre Adventures has produced a unique resource to inspire staff working in mainstream nurseries and special educational settings.

“The Whole Shabang Volume One” “includes a CD of 17 catchy and original songs accompanied by MAKATON signs, musical score and a wealth of practical and creative ideas to enhance learning.

The resources in this unique book have been developed over years of hands on experience in nurseries and special educational settings by musicians and theatre practitioners Russ Elias and Kim Reuter of Shabang! Theatre Adventures with quirky and delightful illustrations by Kath Stewart. Using two themes - the SEA and the GARDEN this creative resource features songs to start and end your day, songs to build language and facilitate group sessions and songs to encourage participation and turn taking. Combined with MAKATON signs the songs come alive to enhance any curriculum including a multi-sensory approach towards every individual song and a DIY toolkit packed with ideas to promote three-dimensional learning.

It also features a step-by-step guide related to EYFS assessment scales, NC attainment targets and ‘P’ performance scales for special needs.

"A rich medley of catchy songs that transport children into imaginary world and role play and encourage listening, participation, and enhance social skills. The resource book provides invaluable support for practitioners who wish to incorporate enjoyable imaginative activities into learning which develop language and communication skills and relate to the EYFS and National Curriculums".

Una Bulman, Former Early Years University Senior Lecturer in Initial Teacher Training

Ways to buy the book:
T 01484 848073 W shabang.org.uk E shabang.info@gmail.com
Price Book & CD £19.99 + p&p CD only £7.99 + p&p

REPORT BACK

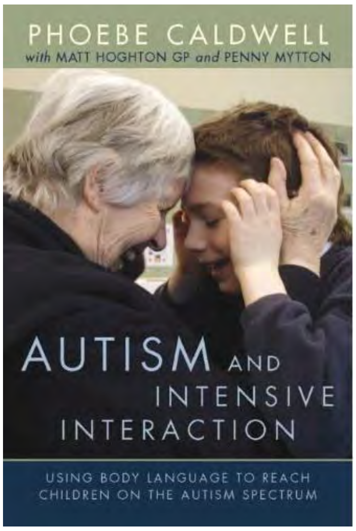
National Forum for Neuroscience & Special Education Conference

In February this exciting new national forum was launched in London, facilitated by Barry Carpenter from The Schools Network. Uta Frith, from University College London set the scene for the day and for the role of this new forum in her opening session - ‘Creating a Two-Way Dialogue’. It explored the clear need and the potential for closer collaboration between those concerned with special education or working in schools and those working in the neuroscience world. Other key experts explored these potentials for our joint learning and discovery, with some excellent and thought-provoking presentations from Francesca Happé, Tony Charman and Amanda Kirby. In the afternoon, Rona Tutt expertly presented our current education situation as an ideal context for moving forward –together. This was valuably followed by 3 excellent presentations describing such collaboration between schools and neuroscience professionals – examples that were clearly grounded in real practice. The potential of such collaborative working was evident to us all!

For more information about the presentations on this day and future events of this forum got to: https://www.ssatrust.org.uk à follow link for Inquire and then The National Forum for Neuroscience and Special Education

REVIEWS

Title: Autism and Intensive Interaction
Using Body Language to Reach Children on the Autistic Spectrum
Author: Phoebe Caldwell
DVD: £19.99 2010, 32pp ISBN: 978-1-84905-088-3, BIC 2: MMZ VFJD



This DVD is the latest publication of Phoebe Caldwell. Phoebe has worked for over thirty five years with people with severe and profound learning disabilities and autistic spectrum conditions of all ages. She believes passionately that as many people as possible, especially family members, should be aware of the simple ways in which they can interact with people considered difficult to reach. Intensive Interaction is one powerful way of doing this. The DVD focuses on her use of this approach in a school for children with autistic spectrum disorders and learning difficulties. Her previous DVD 'Creative Conversations' focussed on the use of Intensive interaction with people with multiple disabilities.

The pack itself is well produced and contains well filmed examples of Phoebe and staff at the school using Intensive Interaction with some of the children in classroom settings. Included in the pack is a simply written leaflet giving some background and providing a guide to the film. The DVD itself is broken into three parts, each with further sub sections, easily navigated on screen by the menu – very useful when using the DVD in training for example.

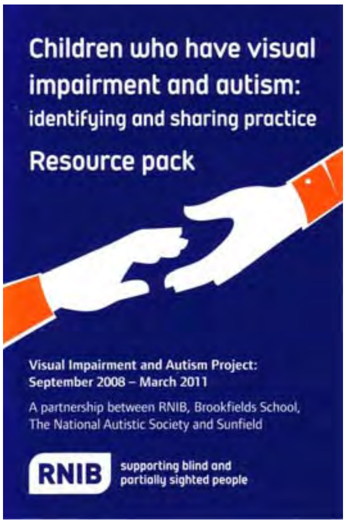
The first two sections cover issues related to sensory differences in people with autism and issues of age appropriate behaviour and the use of touch. Both have application to people with profound and multiple learning disabilities as well as autism. The third section is a completely unedited piece of film where a young child, Jamie, moves from an apparent disinterest in interacting with the adults present in the room into a delightful exchange with Phoebe using a range of non verbal interactions.

Although not specifically aimed at people with profound and multiple learning disabilities this DVD is a useful addition to a range of DVD material now available illustrating the use of Intensive Interaction. This DVD illustrates an approach that can be of real value to any person marginalised from important human contact due to their complex communication needs and will be of interest to anyone interested in the emotional and communicative well being of people with complex communication needs.

Review by

Sue Thurman
Communication Concerns
Speech and Language Therapist and freelance consultant and trainer

Title: Children who have visual impairment and autism: identifying and sharing practice - Resource pack
Authors: A partnership between RNIB, Brookfields School, The National Autistic Society and Sunfield
Price: £10
Available from: RNIB Web: www.rnib.org.uk/shop



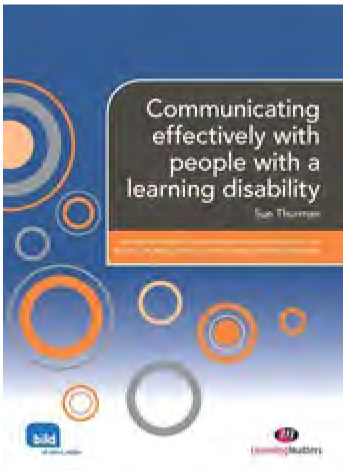
Developed as an outcome of a three year project, this is a useful and thoughtful guide with a great deal of information on a single CD-Rom. Clearly laid out with case studies, a glossary of terms, suggested strategies and resources, it is aimed at teachers, teaching assistants, therapists and mobility officers, but it will also help families to be aware of some of the ways in which they can help their child cope with the dual impact of visual impairment and autism.

One of the key aspects of the project is that it has highlighted the issues that are likely to cause problems and these are addressed in the Strategies section under headings such as 'Managing the environment' 'Promoting peer interaction,' 'Supporting sensory needs.' Each heading leads to sub sections with explanations of the underlying principles and has examples of strategies used by practitioners working with an individual child. Other practitioners may well use different strategies and feedback on the resource is invited via email. Throughout the text there are links to other sections so that one can quickly check a meaning or another principle.

The Glossary contains information on eye conditions, visual awareness, aids and systems, and on autism and related issues, as well as a description of other learning disabilities, and the Resources section is really excellent for equipment, websites and references, and includes live links to research papers.

Although designed for a specific need, the underlying principles do also apply to other children with special needs including those with profound and multiple learning difficulties and it is a resource that needs to be shared.

Review by
Chris Fuller
PMLD LINK



Title: Communicating effectively with people with a learning disability
Author: Sue Thurman
Published: In 2011 jointly by Learning Matters Ltd and the British Institute of Learning Disabilities.
ISBN: 978 0 85725 510 5 (pbk)
Price: £13.00

This book explores why effective communication is important and how to meet the communication and language needs of adults with learning disabilities, taking due account of their individual preference and wishes. It considers the range of barriers to communication and how to overcome them. It also looks at how to workers should respect the principles of confidentiality in all that they do.

This book refers to some real life people with learning disabilities and the people who support them. Each chapter identifies learning outcomes for the reader and provides thinking points to encourage the reader to reflect on practice. It has useful information and encourages the reader to think about how they might apply these ideas in their workplace. Key points are summarised at the end.

The author has worked as a speech and language therapist with children and adults with learning disabilities for 30 years. She writes very well and the text is easily accessible. The book is neatly laid out and is well-illustrated. Terminology is carefully explained. References for further reading and useful websites are given.

The book is designed to support the Level 2 and 3 Diplomas in Health and Social Care (learning disability pathway) and the Common Induction Standards. In practice, anyone who is starting work with people with a learning disability will find this an extremely useful and thought-provoking book.

I especially liked the emphasis throughout upon attending to what people with learning disabilities say to us and making sure that they are sensitively supported to communicate. This is a book for people working with people with a range of learning disabilities but there is much in here that is relevant to people with PMLD. Do take the opportunity to explore it.

Review by

Rob Ashdown
PMLD Link editor

SHORT COURSES & CONFERENCES

Providers Details

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

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

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

Florich Productions and Hirstwood Training
Tel. 01524 42 63 95
Email: flocatalyst@aol.com
richardhirstwood@gmail.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

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

April 2012

Date: April 18th Larbert, 26th Edinburgh, 30th Dundee, May 3rd Glasgow, 17th Aberdeen
Title: 'How do you want me to talk to you?' – supporting practitioner communication with children with exceptional healthcare needs. *Free workshops*
Provider: CEN (National Managed Clinical Network for Children with Complex and Exceptional Healthcare Needs)
Contact: Anna Gardiner - Administrator Email: annagardiner@nhs.net

Date: April 20th Manchester, 23rd London May 11th Leicester, June 12th Birmingham, 15th Bristol
Title: iPads and iPods in special and inclusive education
Provider: Florich Productions Hirstwood Training
Contact: See provider details

Date: April 23rd Birmingham, June 29th Sheffield
Title: Communication with people with learning disabilities
Provider: BILD
Contact: See provider details

Date: 23rd - 27th
Title: International On-Line Conference. Baby Brains Around the World Project: 3rd UK Neuropsychology Symposium: Early Brain- Behaviour Relationships and Prognostic Indicators
Provider: UCL Institute of Child Health
Contact: Tel: ICH Events Team on 44 (0)20 7905 2675 or +44 (0)20 7905 2699
Email: info@ichevents.com

Date: April 25th Birmingham, 27th London, June 13th Chorley
Title: Whole Person Communication
Provider: Concept Training
Contact: See provider details

Date: April 26th Chester, May 10th Newcastle, 23rd Bristol, June 12th Leeds, 20th Cambridge, July 5th Crawley/Brighton & Hove
Title: Creative Communication (interactive training for people who support children and adults with PMLD)
Provider: C.A.N. Communicate
Contact: Tel: 01246 767912 Web: www.can-communicate.co.uk

Date: 26th
Title: Makaton Foundation Workshop
Location: Glasgow
Provider: Concept Training
Contact: See provider details

Date: April 26th Doncaster, May 1st Glasgow, 3rd London, 14th Brighton, 30th Cardiff, June 20th Ipswich, 21st Leicester, July 4th London
Title: Intensive Interaction: Connecting with People Who are Difficult to Reach
Provider: Concept Training
Contact: See provider details

Date: April 26th Chorley, 27th Doncaster, May 18th Belfast
Title: Positive Ways of Changing Behaviour
Provider: Concept Training
Contact: See provider details

Date: April 27th London, May 4th Manchester
Title: P Scale Moderation Workshops
Provider: EQUALS
Contact: See provider details

Date: April 27th Bristol, May 18th Liverpool, June 22nd London
Title: Sensory Approaches to Autism
Provider: Florich Productions Hirstwood Training
Contact: See provider details

Date: April 28th Devon, June 30th London, September 22nd Dublin
Title: An Introduction to Play Therapy
Provider: Play Therapy United Kingdom
Contact: Email: ptukorg@aol.com

Date: April 30th Ipswich, May 21st Belfast, 22nd Dublin, 29th Doncaster, June 12th Cardiff, 18th London, 19th Leicester, July 3rd Birmingham
Title: Practical and Effective Ways of using Multi-Sensory Equipment
Provider: Concept Training
Contact: See provider details

May

Date: 2nd Birmingham, 24th Ipswich, 31st London

Title: OCN Supporting Children and Young People with Autistic Spectrum Disorder in an Educational Setting
Provider: Concept Training
Contact: See provider details

Date: May 9th, 10th, 11th, 16th, 17th Leeds, September 17th- 21st Peterborough
Title: Intervenor Course, and for those assigned to work with a Deafblind/Multi Sensory Impaired child or adult Provider:SENSE (in partnership with The University of Northampton)
Contact: Email: sam.cook@sense.org.uk Tel: 01778 392244

Date: 10th
Title: Half-Day Conference: Sensory Issues: are they the Key to Unlocking Autism
Location: Manchester
Provider: EQUALS
Contact: See provider details
Date: 10th *morning session*
Title: First Aid: Epilepsy Awareness
Location: Stourbridge, West Midlands
Provider: Sunfield PDC
Contact: See provider details

Date: 14th
Title: Promoting Choice in End of Life Care for Young Adults (16 - 25 years)
Location: Chorley, Lancashire
Provider: Derian House Children's Hospice
Contact: Patricia Clarkson, Professional Development Lead. Tel: 01257 233300
E-mail: patricia.clarkson@derianhouse.co.uk

Date: May 14th Middlesbrough, June 6th Liverpool
Title: Profound and Multiple Learning Disability – engaging children in learning
Provider: Concept training
Contact: See provider details

Date: 15th
Title: Person centred approaches for people who challenge
Location: London
Provider: BILD
Contact: See provider details

Date: 15th Birmingham, 24th Brighton,
Title: Play for People with Autistic Spectrum Disorder
Provider: Concept Training:
Contact: See provider details

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

Date: 18th
Title: Understanding learning disability
Location: Birmingham
Provider: BILD
Contact: See provider details

Date: 22nd
Title: Intensive Interaction
Location: Stourbridge, West Midlands
Provider: Sunfield PDC
Contact: See provider details

Date: 25th
Title: Understanding the Power of Play
Location: Stourbridge, West Midlands
Provider: Sunfield PDC
Contact: See provider details

Date: May 25th Birmingham, June 29th Manchester, November 16th Glasgow,
Title: Introducing the 'Great Goal Setting System' – a goal setting system for any curriculum
Provider: Florich Productions Hirstwood Training
Contact: See provider details

Date: 25th
Title: An SLD Curriculum for the 21st Century
Location: Manchester
Provider: EQUALS
Contact: See provider details

Date: May 29th Birmingham, June 28th Manchester
Title: Exploring Listening and Talking Hands
Provider: SENSE
Contact: Email: Joanna.Bassett@sense.org.uk Tel: 01372 840306

June

Date: 11th
Title: Supporting a person with learning disabilities in a person centred way
Location: Sheffield
Provider: BILD
Contact: See provider details

Date: 12th Birmingham, 21st Ipswich, 28th London
Title: Inclusive Play
Provider: Concept Training
Contact: See provider details

Date: 14th
Title: Sherborne Developmental Movement Level 2
Location: Stourbridge, West Midlands
Provider: Sunfield PDC
Contact: See provider details

Date: 15th
Title: Penhurst School PMLD Study Day: "Looking to the Future"
Location: Chipping Norton, Oxfordshire
Provider: Penhurst School
Contact: Naomi.Roberts@actionforchildren.org.uk
Tel: 01608 642559

Date: 15th
Title: Communication and autism
Location: Birmingham
Provider: BILD
Contact: See provider details

Date: 15th
Title: Conference: Towards Outstanding Governance in Special Schools
Location: Manchester
Provider: EQUALS
Contact: See provider details

Date: 16th – 23rd
Title: PTUK 2012 Conference 'Preparing for Regulation'
Professional and Therapeutic Skills
Location: Southborough, Nr Tunbridge Wells
Provider: Play Therapy United Kingdom
Contact: Email: ptukorg@aol.com

Date: 18and 19thJune - Bonhill House, London
25 and 26thJune – Future Inn, Bristol

Title: Sleep Practitioner Training 2012
Details: The Handsel Project (Formerly Handsel Trust) is offering the following dates for this 2 day RCN accredited workshop, suitable for health and social care professionals supporting children with disabilities and sleep problems
Contact: Joanne Littlefair
enquiries@handselproject.org.uk

Date: 22nd
Title: Autism and sensory issues
Location: Sheffield
Provider: BILD
Contact: See provider details

Date: 22nd
Title: Autistic spectrum conditions and ADHD in adults with intellectual disability: the need for service development
Location: London
Provider: The Royal Society of Medicine
Contact: Ruth Threadgold. Tel: 020 7290 3942
Email: intellectual.disability@rsm.ac.uk

July

Date: 2nd
Title: Safeguarding and protection for people with learning disabilities and/or autism
Location: Birmingham
Provider: BILD
Contact: See provider details

Date: 3rd
Title: Strategies to Promote Sensory Well Being
Location: Stourbridge, West Midlands
Provider: Sunfield PDC
Contact: See provider details

Date: 10th
Title: Mental Health Issue with ASD
Location: Stourbridge, West Midlands
Provider: Sunfield PDC
Contact: See provider details

Date: 10th
Title: Promoting effective communication with people who challenge
Location: Birmingham
Provider: BILD
Contact: See provider details

Date: 16th
Title: Positive behaviour support to support people who challenge
Location: Sheffield
Provider: BILD
Contact: See provider details

October

Date: 2nd
Title: Promoting the well being of children with complex needs
Location: London
Provider: The Royal Society of Medicine
Contact: Ruth Threadgold. Tel: 020 7290 3942
Email: intellectual.disability@rsm.ac.uk

Date: 28th – 30th
Title: 28th Annual Conference on Young Children with Special Needs and their Families: Realizing the vision
Location: Minneapolis, Minnesota, USA
Provider: Division for Early Childhood (DEC) of the Council for Exceptional Children
Contact: Email: presenter@dec-sped.org
Web site: www.dec-sped.org

Date: May 14th Middlesbrough, June 6th Liverpool
Title: Profound and Multiple Learning Disability – engaging children in learning
Provider: Concept training
Contact: See provider details

Date: 15th
Title: Person centred approaches for people who challenge
Location: London
Provider: BILD
Contact: See provider details

Date: 15th Birmingham, 24th Brighton,
Title: Play for People with Autistic Spectrum Disorder
Provider: Concept Training:
Contact: See provider details

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

Date: 18th
Title: Understanding learning disability
Location: Birmingham
Provider: BILD
Contact: See provider details

Date: 22nd
Title: Intensive Interaction
Location: Stourbridge, West Midlands
Provider: Sunfield PDC
Contact: See provider details

Date: 25th
Title: Understanding the Power of Play
Location: Stourbridge, West Midlands
Provider: Sunfield PDC
Contact: See provider details

Date: May 25th Birmingham, June 29th Manchester, November 16th Glasgow, 19th Preston, 23rd Nottingham
Title: Introducing the 'Great Goal Setting System' – a goal setting system for any curriculum
Provider: Florich Productions Hirstwood Training
Contact: See provider details

Date: 25th
Title: An SLD Curriculum for the 21st Century
Location: Manchester
Provider: EQUALS
Contact: See provider details

Date: May 29th Birmingham, June 28th Manchester
Title: Exploring Listening and Talking Hands
Provider: SENSE
Contact: Email: Joanna.Bassett@sense.org.uk Tel: 01372 840306
Email: intellectual.disability@rsm.ac.uk

LONGER COURSES (with accreditation)

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

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

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

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

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

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

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

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

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

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

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

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

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

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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 covers a wide range of issues of interest and practical use in the day-to-day work of practitioners, parents and carers in schools, colleges, adult provision, in the home, and covers issues pertaining to all groups, including occasional articles by practitioners and parents from overseas. It enables readers to create networks, and provides a forum for contact with others involved in the field. The contributions may be:

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

About Us

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

Rob Ashdown	Headteacher of St. Luke's Primary School, North Lincolnshire, for children with complex learning difficulties
Helen Daly	Mum to a young Adult with PMLD, previous career in Further Education for 20 years - including Curriculum Team Manager for Inclusive Learning and Developing an Improving Choice Programme for people with Complex Needs. Currently involved in carers groups in the Eastern Region, Learning Disability Partnership Board and associated projects.
Beverley Dawkins	National officer for profound and multiple learning disabilities, Mencap
Ann Fergusson	Researcher and tutor for severe learning difficulties and PMLD courses at The University of Northampton. Trustee of National Family Carers Network. Ann also has a family member with a learning disability
Chris Fuller	Founder and former Director of Bag Books: multi-sensory stories for people with PMLD, and previously special education teacher
Penny Lacey	Coordinator of the University of Birmingham course in severe, profound and complex learning difficulties; freelance consultant; Penny has a family member with severe learning difficulties
Loretto Lambe	Director of PAMIS an organisation in Scotland working with people with PMLD, their family carers and professionals who support them
Wendy Newby	Teacher and curriculum coordinator St. Rose's School, Stroud, a school for children with physical disabilities and complex health needs
Carol Ouvry	Retired special education teacher, trainer and consultant in the field of PMLD. Previously editor and administrator of PMLD Link

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