PMLD LINK

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

Winter 2007

Health Matters

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

Health Matters

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

Winter 2007

GUEST EDITORIAL
Winter 2007

Health Matters

Happy New Year and welcome, *at last*, to the delayed Winter issue of *PMLD Link.* Hopefully the seasonal festivities were enjoyable and 2008 will be a positive year for you all.

For some of us however, struggles surrounding the health and well-being of someone we care for or support will be taking its toll. Hopefully the articles and information here may offer just what is needed to make a positive difference for that individual. In fact, this issue is bursting with valuable information!

Recent personal experiences prompted me to ask some authors in this issue to share their information with PMLD Link readers. I discovered the *'I'm talking – are you listening?'* resource when my brother had a sudden, unexplained weight loss. It was a great tool for pooling 'clues' as we tried to solve his situation, but it also made me aware of it's much wider value. Take a look; Jo Hartland is keen for feedback. Thanks to a new website www.lookupinfo.org we finally found a willing and experienced optician and my brother had his first eye and vision test…at the age of 44! Read Gill Levy's article about frequently undetected visual problems, as well as information about a new website and the valuable services it offers. Laura Waite offers similar insight into hearing difficulties.

In response to queries about epilepsy, John Ockenden has kindly researched for us, some responses to those 'frequently asked questions' – along with some possible life-changing suggestions. On that theme of life-changes, Brenda Garrard's article details a very inspiring and comprehensive project by PAMIS, on improving the health of people with PMLD *and* their carers. Jo Giles and Sandra Hill tell us about their experiences of involving people with learning disabilities in promoting their own positive health. From the health professional angle, we have a thought provoking essay from a final year medical student examining ethical issues involved in treatment. Janet Cobb alerts us to a worthwhile network for those involved in Health and learning disability services.

As usual, our News section has information on campaigns and other developments – including updates on Mencap's 'Death by Indifference' report, positive progress on Changing Places and many valuable health –related resources. It's like Christmas all over again!
Do send us your feedback…is this what you want to read about?

Wishing you all a happy *and healthy* 2008!

Annie Fergusson

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I'M TALKING – ARE YOU LISTENING?

Jo Hartland
Home Manger, Mencap

Imagine, if you can, you have toothache. Not a raging pain but a dull ache that has gone on for several days and you can't tell anyone. Or, on a lesser scale, that every time you are dressed you start to itch, but again you can't tell anyone. At an even more disturbing level, if someone was hitting you (or any other form of abuse on a regular basis), but, once again, you couldn't tell anyone. If you can put yourself in this situation, then you can understand why the resource "*I'm talking – Are You Listening?* " was created.

As one of Mencap's Registered Home Managers, I had felt for some time that our organisation's formal complaints procedure excluded service users with PMLD from making a complaint, as it was simply not "user friendly" in their circumstances. A gap existed through which people with PMLD fell. They were unable to 'voice' any complaint that they might have, particularly if the complaint was about any form of abuse, or of an equally serious nature.

So to address this gap, I set up a multi-disciplinary group comprising of myself Jo Hartland, Registered Manager (Mencap), Ann Hancox, Speech and Language Therapist, (Worcestershire Health Authority), Michelle Merryweather, Community Nurse, (Worcestershire Health Authority), and Ken Timms, Psychologist, (Worcestershire Health Authority). Each member of the group was allocated a specific area according to their expertise, for example the Speech Therapist produced a section on communication giving factors to consider if there was something different in a person's behaviour or communication.

All this information was then collated and a resource pack was produced. The pack included notes for both Carers and Managers, a flow chart which detailed the format and how to follow the procedure and a number of forms to detail any concerns about changes in behaviour of a particular service user or whether there were significant concerns which required any action to be taken. It was emphasised that if the concern was such that any form of abuse was suspected then the Manager should be notified immediately.

This is how it was envisaged at the outset that the information gathered using this resource would be used. It was then realised that the procedure could also be used as a quality audit tool for wider concerns in people with PMLD, including health matters.

Even if no specific areas of concern had been identified, this resource could flag up something as simple, for instance, as the need to change something the service user didn't like. For example, if on several occasions a service user had thrown down a drink - it might indicate that they didn't like the cup used, they didn't like that particular drink, they had been given or even, if it was on the occasion that a cold drink had been given and they perhaps had a dental problem which required investigation. Simple things in themselves, but for someone with PMLD, almost impossible to communicate to anyone.

At the moment this procedure is still in the pilot stage and workshops have been undertaken by Mencap's Western PMLD Group. The trials have been targeted at Managers and Carers, who have been asked to bring examples of "best practice" and this is where we have introduced the "I'm Talking – Are You Listening?" pack. We have issued feedback forms so that any suggestions or issues may be raised, discussed and the information provided can be reviewed.

None of us know what someone who has PMLD feels or thinks because communication is limited to them but we hope that perhaps the use of "I'm Talking – Are You Listening"? might, in a very small way help to turn communication for them into a two way process.

Jo Hartland

If you would like further information, perhaps a written copy or an electronic versions of the complete pack please contact Jo Hartland on 01926 492235 or
Email H5M021Hartland@mencap.org.uk.

EDITOR'S Notes:

The challenge we so often face in providing the best support and care for people with PMLD, is that of getting the *whole picture*, to then be able to take the best plan of action. Health is frequently an area we have to make '*best guesses*' - have they perhaps got a sore throat or a headache?…How *do* we know, beyond the ‘gut feelings’, that all is not well?

To add more insight into such quests, this tool can aid our ‘detective skills’ by providing some clear prompts to find more clues or even answers. The essential information generated, when seen holistically, helps get to the nub of the possible problem - and may even provide some solutions.

I have included some excerpts from this resource here, to illustrate its value. Although it is not written into the ‘instructions for use’, you will see how the tool lends itself to be used collaboratively – for example by day and night-time staff; the home, family members, carers and day service staff. Each person may provide just that essential bit of information needed to complete the bigger picture. The completed audit also offers a wealth of information if referrals to other professionals need to follow on.

The focus on Health includes specific examination of the following:

General health & physical appearance; Teeth & oral hygiene; Eyes; Ears; Skin; Hair & scalp; Continence; Epilepsy; Appetite; Mobility; Posture; Menstrual Cycle; Medication; Sleep; Blood test & urine test; Any other. Mental Health: Anxiety; Obsessive; Compulsive Behaviours; Depression; Any other.

EXCERPT 1:

Carer Guidance Notes
For completion of “I’m talking - are you listening?”

- Firstly complete the Personal Profile section giving a brief explanation of what is “normal behaviour” for the client. This can be done from the carer’s own knowledge of the Service User, together with information taken from other relevant documentation e.g. Care Plan, Person Centred Plan (PCP), Health Action Plan (HAP) etc.

- As keyworkers and carers you are best placed to notice anything different, any changes in the behaviour or communication of your client. This would indicate a need to implement this procedure, by reference to the flow chart. It is important that at this point you inform your Manager of your intentions and that you keep them fully briefed at all stages of the procedure. They must be informed immediately of any findings, so that action can be taken to address the situation.

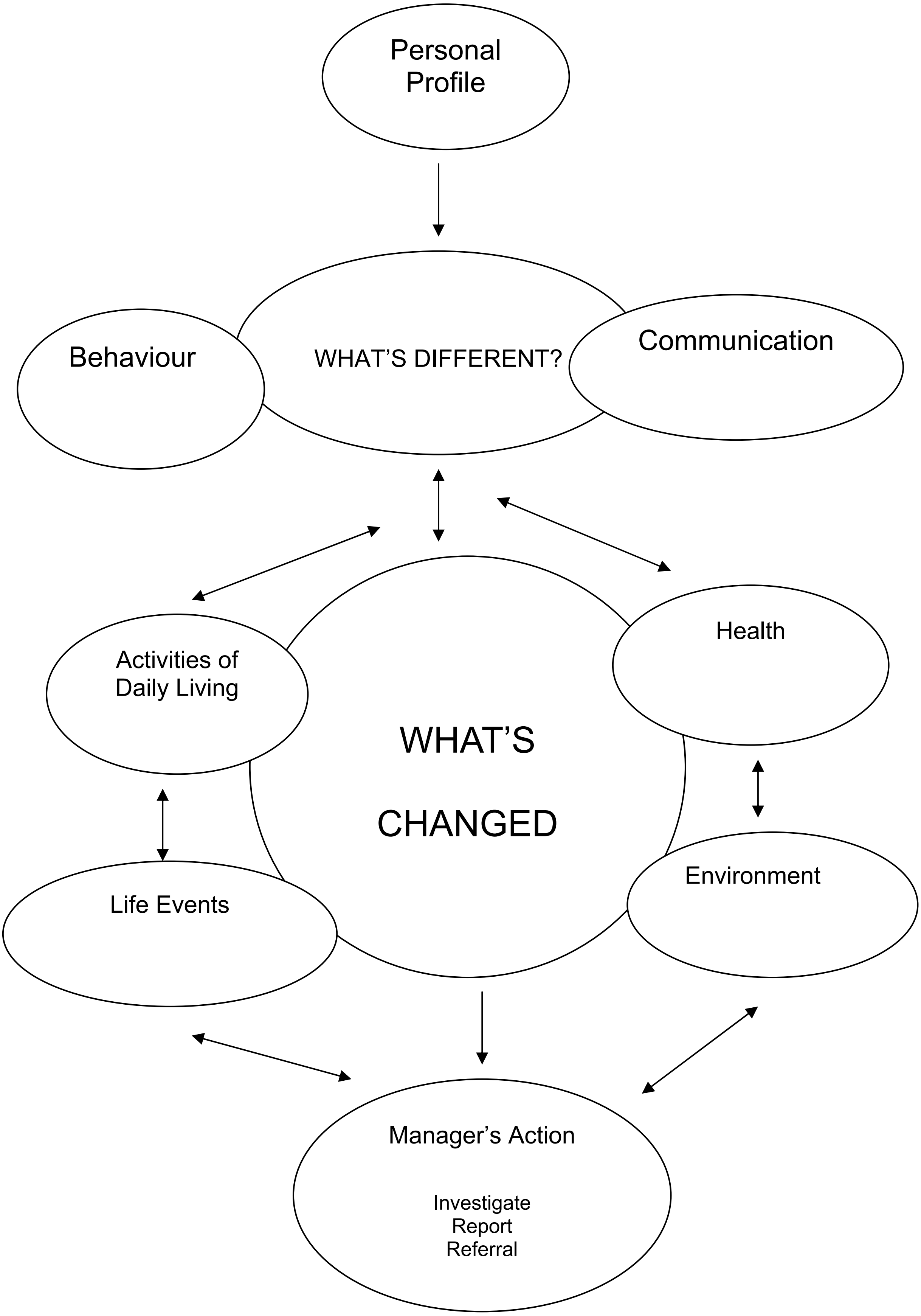
- Having identified a change in either behaviour or communication, complete the appropriate form headed either, ‘WHATS DIFFERENT’ - BEHAVIOUR’ or ‘WHATS DIFFERENT - COMMUNICATION’. Note any significant areas of concern and just as importantly, place a tick against the areas which are not causing any concern. In this way a complete picture will start to form.

- Following the flow chart you are lead to the ‘WHATS CHANGED’ circle. There are four areas, which may contain a cause of the change in behaviour or communication, ACTIVITIES OF DAILY LIVING, LIFE EVENTS, ENVIRONMENT AND HEALTH. Following the same procedure used for completing the previous forms, complete one form for each of the areas, once again being careful to note any areas of concern and also any areas which are of no concern.

- All the completed paperwork should be collated and passed to your Manager as supporting evidence for any concerns you have raised.

- If no significant concerns are found “No Concerns” boxes are ticked and the entire pack should be passed to the Manager, who will gather together any necessary additional information e.g. care plan, assessments, and any ABC Charts. These will then be used to support and refer to the appropriate professional e.g. GP, Psychiatrist, Speech and Language Therapist, Community Nurse etc, for further input and investigation.

EXCERPT 2: Overview of Audit Process
From of “I’m talking - are you listening?”



What's Different: - Behaviour

Behaviour:	Factors to Consider	No Concerns	Significant Concerns	Action / Comments	Date	Signature
When you're together	More clingy; more distant; pushes away; not looking at you; tries to hit, pinch or bite; doesn't smile; laughs too much; doesn't respond to your usual greetings / interactions; swearing; follows you around more; more upset if you are getting ready to go.					
When on his/her own	Crying; hitting self; hitting out at furniture; hitting out at passing staff; laughing to self; hard to get attention; doesn't respond to staff / other people as usual; biting / pinching / hitting self; shouting; pushing favourite objects away; looks frightened.					
With other people	Doesn't want to join in; moves away from people; pushes people away; tries to cuddle people; tries to get people to touch or be with him/her more than usual; "too affectionate"; hitting out; shouting at others.					
Other people change their behaviour to him/her	Other people keep their distance; other people shout at him/her; other people complaining about him/her; other people giving lots of attention/concern.					
Behaviour:						

EXCERPT 3: Sample of one area
From of "I'm talking - are you listening?"

Epilepsy and People with PMLD

John Ockenden
Practice Development Team, united Response

Substantial numbers of people with PMLD are also affected by Epilepsy. A national report earlier this year [The All Party Parliamentary Group On Epilepsy, 2007] suggested that many people with a learning disability are not getting appropriate treatment for their epilepsy. It can be difficult to judge whether epilepsy really is being treated optimally for a number of reasons:

- It's so common for people with a learning disability [and even more so people with PMLD] to have epilepsy that it can be viewed as an inevitable consequence of the learning disability and completely resistant to treatment
- There is a widespread lack of awareness of what treatments are available and what outcomes are possible – particularly amongst those who can advocate on behalf people with a learning disability
- Continuing poor general health support for people with a learning disability

There is currently no detailed comprehensive official guide for people with a learning disability and their carers and supporters, on what services and outcomes they can expect for epilepsy.

This article is designed to help readers judge whether people they support or care for are receiving optimal health input for their epilepsy. It's based on a review of guidelines, literature and research, as well as discussion with a number of epilepsy experts who have kindly contributed their knowledge and understanding.

For clarity, the issues are described as a series of questions and answers.

1. How do I know if the person is getting the right epilepsy care?

a National Institute for Clinical Excellence guidelines [NICE, 2004] state that the management and treatment of epilepsy for a person with a learning disability should be undertaken by an epilepsy specialist working within a multidisciplinary team. It appears that this is not the experience of many people.

There is no widely agreed definition of what an epilepsy specialist is but epilepsy experts suggest that someone can only be described as an epilepsy specialist if

i They have evidence of training and continuing professional development in epilepsy
ii Their clinical practice includes the equivalent of at least 1 session per week of epilepsy [that's about 4-6 new and 5-10 follow up patients per week

b Some learning disability psychiatrists, GPs, neurologists may well be epilepsy specialists in addition to their normal work – but many won't.

c Epilepsy Action [the working name of the British Epilepsy Association] maintain a database of epilepsy specialists around the country. You can contact them direct [helpline@epilepsy.org.uk] to enquire about epilepsy specialists local to you.

d NICE state that if one or more of the things listed below happen, a person should be referred to a Tertiary Epilepsy Service [ie a specialist epilepsy clinic or unit]

i. Anti-epileptic drugs [AEDs] do not control seizures within 2 years
ii. 2 AEDs in combination have been tried unsuccessfully
iii. iThere are unacceptable medication side effects
iv. There are doubts about the diagnosis

It seems that many people who should be referred under these criteria are not – epilepsy specialists report that they receive many fewer referrals than there should be if these guidelines were being followed or if patients or their carers or supporters knew what to ask for, and understood the benefits of specialist input.

So if you are concerned that a person you support fulfils the criteria for a referral to a Tertiary Epilepsy Specialist but hasn't had one, you can discuss this with whoever is managing the person's epilepsy at the moment, quoting the NICE guidelines. If you want to know where the nearest Tertiary Epilepsy Specialist is, you can ask the Epilepsy Action helpline

2. What should good epilepsy care include?

a. Diagnosis

Most readers will be familiar with many of the tools used in diagnosis: taking a history and description of seizures, EEG and neuroimaging [MRI or CT]. NICE furthermore recommend the use of video to record seizures where getting a clear history and description is difficult – this could be particularly relevant for people with PMLD [although issues of consent, best interests and dignity may need to be considered in this context]

In addition the use of video-telemetry is recommended – this involves running a video camera and EEG simultaneously so as to tally what's visibly occurring to the body with what's going on in the brain. Again this may be particularly useful where people have difficulty in explaining what's happening to them, although for people with PMLD it may be difficult to interpret the EEG because it is may be unusual even without the epilepsy.

b. Treatment – AEDs

The most common treatment for epilepsy is the use of AEDs. The best outcome is that seizure freedom is achieved by treatment with a single AED – but this is less likely for people with a learning disability than for non-disabled people. If 2 different drug combinations have been tried without achieving freedom from seizures then the person should be referred to tertiary services.

Combinations of more than 2 drugs are unusual in the general population, but are more likely to be tried with people with a learning disability, because the epilepsy is likely to more severe.

Interestingly the NICE guidelines state that blood tests should not be carried out routinely, but only in a limited number of circumstances [e.g. suspected toxicity, taking Phenytoin]. If the person you support is regularly having a blood tests it would be worth checking why.

c. Treatment – others

In addition to AEDs people may be treated with Vagus Nerve Stimulation [VNS] or with Surgery. VNS involves an operation to fit an electrical stimulator to the Vagus Nerve in the neck via the chest [a bit like a pace maker]. This may reduce the frequency of seizures for people with severe epilepsy.

Surgery has always been a possibility but is viewed with caution, as it needs not to cause more problems than it solves. 3% of people with epilepsy would benefit from surgery, but there are increased risks for people with a learning disability so that while it should be considered and discussed, and is probably underused in people with a learning disability, it is less likely to be pursued than in the non-disabled population.

3. What outcomes should be expected from good epilepsy care?

a. The aim of good epilepsy care should be to achieve seizure freedom, or if not possible, seizure reduction. In the non-disabled population seizure freedom is currently possible for about 75% of people. For people with a learning disability the comparable figure appears to be about 40%, although the actual number who achieve this currently is a lot lower.

b. You should expect a referral to a Tertiary Epilepsy Service where seizure freedom is not achieved, and an epilepsy specialist to explore all of the above treatment in pursuit of seizure freedom. Much of the gap between reality and what is possible appears to arise because people aren't referred to an epilepsy specialist.

c. The NICE guidelines suggest that withdrawal from AEDs should be considered when the person has been seizure free for 2 years. While the risks may be considered too great [because of other damage to the brain associated with the learning disability], this is something that should at least be discussed with the epilepsy specialist. In order for them to make a clear decision about this, they will need long term information about the person's epilepsy [eg. going back to childhood if the person is now an adult]

4. What does an Epilepsy Specialist need at an appointment?

Epilepsy specialists need good information in order to deliver good care – sometimes this doesn't happen. For appointments to optimise the chances of the person with PMLD getting the best out of an epilepsy specialist, they should involve

a. Someone [support worker, carer or other] who knows the person with epilepsy well
b. Details of current medication
c. Details of seizure frequency
d. Descriptions of seizures
e. Where possible, details of past medical history

5. What if seizures carry on even with the best available care?

Refractory Epilepsy [ie where the epilepsy is resistant to treatment] is currently not uncommon for people with a learning disability. The NICE guidelines state that if AEDs fail to control seizures it may be better to stop medication. However epilepsy specialists working with people with a learning disability argue very strongly that, although it should be considered, it should only happen in the small minority of circumstances when a person has mild focal seizures.

6. Why do people with a learning disability [and particularly people with PMLD] experience poorer outcomes than non-disabled people, even with the best available diagnosis and treatment?

a. Learning disabilities are often caused by physical damage to the brain – such damage is often the focal point for the development of seizures. Other consequences of the disability, like unusual ways that the brain has developed since being damaged, can make understanding how the brain is working difficult, and can make treatments less effective than they would be in a non-disabled brain
b. The more learning disabled a person is the more likely they are to have epilepsy and the more resistant to treatment their epilepsy will be – so that's going to be particularly the case for people with PMLD
c. Diagnosis and management is complicated when people have difficulty with describing [and more so if they can't describe] their symptoms and the consequences of treatment – and when they're dependent on others to describe them
d. Some people with a learning disability have movement disorders or may behave in ways that makes it difficult to appreciate that epileptic seizures are happening, or what form the epilepsy is taking
e. Epilepsy in people with a learning disability [and particularly PMLD] is more likely to involve higher seizure frequency and multiple seizure types than for non-disabled people – this again makes effective treatment harder to achieve.

7. **What are the consequences of uncontrolled epilepsy?**

Most readers will be aware that

a. When a person has a lot of seizures, or some severe seizures, over time, there is every chance this will cause further damage to the brain.
b. Status epilepticus [continuous seizures] can be fatal and requires immediate treatment. It is now usual for support staff and carers to be trained to deliver rectal diazepam or buccal midazolam, and then only progressing to calling out paramedics and hospital admission if an agreed protocol suggests it
c. Seizures significantly affect people's quality of life and interfere with the ability to take opportunities for engagement and to develop and maintain status and relationships. Where people share living arrangements and support, one person's seizures are likely to affect other people's quality of life

In addition it's worth noting that Sudden Expected Death in Epilepsy [SUDEP – literally an unexplained death where an epileptic episode may be implicated] was found to be 3 times more likely in a study of young people with a learning disability that compared them to the non-disabled population – it's not unreasonable to suggest this may be due to a higher occurrence of seizures, thus implying that every effort should be made to reduce seizure frequency, and ideally achieve seizure freedom

Some people with PMLD will be receiving excellent care for their epilepsy – but current research and reports suggest that some will not. Epilepsy in general has historically been poorly understood, researched and funded. And as suggested it's hard know what's unfair and the result of discrimination, and what does really come with the territory. The evidence currently is however that substantial improvements in epilepsy care are available for many people. It is hoped that this article will help those who support and care for people with PMLD to identify opportunities for improvement in the epilepsy care they receive, as well as promoting further discussion in future editions.

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Thanks are due to Dr Hannah Cock of St George's University London, and Professor Mike Kerr of Cardiff University for their help in preparing this article.

References

All Party Parliamentary Group on Epilepsy [2007] **The Human and Economic Cost of Epilepsy in England: Wasted Money, Wasted Lives** available from http://www.jointepilepsycouncil.org.uk/inquiry.asp

National Institute for Clinical Excellence [2004] **Diagnosis and Management of the Epilepsies in Adults and Children in Primary and Secondary Care** available from http://www.nice.org.uk/pdf/CG020NICEguideline.pdf

Epilepsy Action's website is at http://www.epilepsy.org.uk/, the National Society for Epilepsy have a website at http://www.epilepsynse.org.uk/ .

Spring Vol. 20 No. 1 Issue 59

- Families -

The copy date for all articles, information and news for the Spring 2008 issue is the
7th March

Please send contributions to:
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Summer Vol. 20 No. 2 Issue 60

- Community Partnerships -

The copy date for all articles, information and news for the Summer 2008 issue is the
6th June

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

Look Up – a new information service on eye care and vision for adults with learning disabilities

Gill Levy
Information Officer, See Ability

SeeAbility and RNIB have launched *Look Up*, an information service on eye care and vision for adults with learning disabilities, family carers, staff in health and social care and eye care professionals.

Information will be 'delivered' in four ways:

- Publications and resources
- Website - www.lookupinfo.org
- Telephone line - 0800 121 8900
- Email forum – to be launched later this year

The collaboration between SeeAbility and RNIB has enabled the Look Up team to update material produced by RNIB's now-disbanded Multiple Disability Team. We are also developing new publications and resources – new leaflets on eye care, a DVD on sight tests and cataracts. Later we will publish material on hearing care, communication and teaching and learning skills.

We are campaigning for people with learning disabilities to have access to high quality eye care so we are working with eye care professionals in the community and hospitals. We also want to ensure that people get appropriate and timely help when a visual impairment is identified.

This article highlights considers sight problems in people with learning disabilities and includes snap-shots of different people with severe/profound and multiple learning disabilities. It shows how people have benefited from having their sight problem identified and better understood.

Research information

The NHS Executive suggests that 'About 30% of people with learning disabilities have a significant impairment of sight…. There is a high rate of under-detection of sensory impairments, most of which can be treated'. (1998, Signposts for Success).

This means that there are two 'groups' of people with sight problems:

- People who are blind/severely sight impaired or partially sighted/sight impaired and need appropriate help
- People who have difficulty seeing because they need glasses, eye surgery or other treatment to improve their sight.

Sight problems

A sight problem will have a 'knock on effect' on a person's other impairments or disabilities – so it is important that the meaning of their visual impairment is understood. Surveys consistently suggest that the people with limited skills are more likely to have a visual impairment.

Thousands of people with learning disabilities who do not see well need glasses – and support to become comfortable wearing them. People may be

- short sighted
- long sighted
- astigmatic (when vision is distorted because the front surface of the eye is more curved in one direction - more like a rugby ball in shape than round like a football).

A very small percentage of blind people have no sight whatsoever. A minority have light and dark perception only.

Most blind people have some useful vision, which they can use in their daily lives. However people need help to make the best use of their vision.

People with sight problems are different:

- Some people see the world as a blur - like a series of abstract pictures in muted colours.
- People may have problems with their visual field (all round vision). They may only see a small part of the whole or only see objects on one side or other, or the upper or lower fields of vision.
- Others may have tunnel vision (central vision) and have difficulty seeing what is on either side of them),

- Many people have distorted colour perception. The world may seem yellowy or dirty.

Different eye conditions present people with different problems in their daily lives. People are individuals. People with the same eye condition may not see things in the same way. They may face different problems in the course of their lives – and at time may need different solutions.

Variations in vision

Each person's sight and the way he/she uses it is unique to that person. They will not always see the same things in the same way. A person's sight may alter considerably throughout a single day. Indeed some people's sight can vary over very short periods; environmental factors and personal issues affect it, such as

- lighting
- colour contrast and use of colour
- health
- time of day – is the person tired?
- anxiety – is the person feeling stressed?

Sighted people watching blind and partially sighted people are often confused because they wrongly believe that an individual's sight is static and unchanging. They may say, quite incorrectly, "she can see when she wants to".

Thinking about individuals

Many people with PMLD were born with a visual impairment; while others lose may their sight with ageing and/or preventable eye conditions.

It is vital that people are supported to have regular eye tests. An increasing number of people have successful cataract surgery.

Sight loss is stressful. People with PMLD may have only their behaviour with which to tell supporters that their vision is deteriorating. Some people become withdrawn and fearful, while others develop behaviour that communicates their overwhelming distress. These behaviours are often misunderstood. (Two new leaflets on sight loss will be on The Look Up website soon).

Individual stories

Sadly, many people have stereotyped views about sight problems – often because they have not had training in visual impairment.

The following snap-shots highlight some issues for individuals and the people who support them.

Short sight: 'We thought that George was over-friendly coming up close to new people and invading their personal space. As he was over 6' tall, many people found this intimidating. Then we found out that he needed glasses. He got close up so he could recognise people's faces. The glasses have solved the problem totally'. (Information about eye tests and glasses is on the Look Up website)

Long-sight: No-one thought Marina could ever eat independently as her co-ordination was so poor. An eye test established that she was very long-sighted. She could not focus on near things - so she could not use her eyes to direct her hands. The optometrist prescribed half-strength glasses, as he felt she needed time to build up to a full prescription. Everyone was delighted when she eventually accepted her new glasses. She soon learned to use a spoon and to spear things with a large-handled fork. Within a year she had learned skills that people had not considered her capable of learning.

Blurred vision: Susie was born with blurred vision. She can walk about independently in well-lit settings. But she has night-blindness and needs help in dimly-lit corridors. She benefits from basic low vision techniques – such as good colour contrast (doors which contrast against a wall, red cups on a white table-cloth) and clear even lighting. Susie finds bright lights painful – especially sunlight – and likes to wear a hat in the summer. If no hat is available, she is likely to be 'difficult' and refuse to go out.

Sight in the corner of one eye: Kathy was viewed as a challenge! It was hard to engage her in activities and to prevent her from falling asleep all the time. Initially everyone thought it was medicine for epilepsy that made her sleepy, so this was checked. However, a sight test showed that she had sight out of the corner of one eye only. This meant that we had to park Kathy's wheelchair in just the right position for her to join in with things. She was not able to turn her head or move her body to successfully use her small amount of vision without our help.

Tunnel vision – Suddenly Jason hit his key-worker. Everyone was surprised as he was clearly fond of her. The manager of the home had noticed that Jason had begun to walk very slowly, feeling his way with his feet. She had suspected his sight might have deteriorated. It was found that he had tunnel vision, caused by glaucoma which other members of his family also had. Anita, his key-worker, had startled Jason by approaching him outside his 'frame of vision'. When people approached Jason from the front, he could see them coming and smile at them.

Cataracts – not dementia! When Rosie started getting lost in the home where she had lived for many years, the staff assumed that she had developed dementia. 'After all, she was 40+ and had Down's syndrome'. However, her support worker convinced his team that she needed an eye test – and it was found that cataracts in both eyes were the cause of her behaviour changes. (Information about eye surgery is on the Look Up website)

Strange head position: Gordon would often sit with his chin resting at an angle on his left shoulder. He would arch his back from time to time. The optometrist suggested that Gordon might have adopted this strange head position to get the best out of his patchy vision. The rehabilitation officer for the visually impaired (ROVI) and Gordon's physiotherapist had to work together to ensure he could use his vision without putting additional strain on his already vulnerable neck and spine.

Behaviour misunderstood – One mother was convinced that her daughter, Maureen, was a 'lovely easy-going personality', who happily 'just sat at the day centre, waiting for things to happen'. Later it was found that Maureen had very poor sight. She did not move by herself because she 'did not know what was out there'. The team approached the local sensory impairment service, who suggested minor adaptations to the environment, such as tactile markers, doors that contrasted in colour against the white walls. Maureen has changed from being 'a passive sitter' and is much more active now.

Sight and hearing: It was always known that Jimmy had a hearing impairment. At his review it was noted that he seemed to have become deafer in recent months. However, a hearing test showed that his hearing had not changed, but an eye test found that he had become more short-sighted. This had affected his communication skills, as he was very dependent upon his vision to watch people's faces and body language to make sense of what is going on around him.

Eye-poking, a harmless habit? The staff had always been told that eye-poking was just a mannerism enjoyed by children and adults who were born with little or no sight. But they were concerned that Sally's eyes looked so red and sore. The GP referred Sally to an eye hospital, who confirmed that Sally had developed a secondary eye problem, which needed urgent treatment to save her remaining vision. (A new leaflet on eye-poking will be on our website soon).

Taking action

Sight and hearing problems are so common in people with profound and multiple learning disabilities that we should be actively looking for them!

But it is not enough to identify sight problems. We must ensure that the people get the right help at the right time to prevent their quality of life being undermined.

Do contact the Look Up team if you would like further information

Gill Levy
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Email: g.levy@lookupinfo.org
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Exciting new website live in April 2008!

Jo Giles
Generate

Generate, an organisation in South West London, is launching an exciting new website in Spring 2008.The main aim of easyhealth.org.uk is to make it easier for people to find good quality health information that is easy to understand.

The website is called easyhealth.org.uk and it is funded by The Department of Health.

How does it do this? By bringing together good quality accessible health information from across the country, and putting it onto one website so that people can choose the information that suits them and can download straight away.

Why is Generate doing this? A few years ago Generate delivered training in over 30 local GP surgeries and feedback from nearly all was, ‘Where can we find health information that is easier to understand?’

It seems to be a common experience for all sorts of people that this information is hard to find. Then, often when (and if) this information is tracked down, there is a cost to it and a delay for waiting for the information to come in the post..

Generate wants to reduce these barriers and ensure that people get information when they need it and how they need it.

We are working with a wide range of organisations to get their health information onto easyhealth.org.uk so that: people can go to one place (online), look up a health issue of their choice, find a range of accessible leaflets to choose from, and then read from the screen or download it straight away.

By getting good quality health information that people can understand into one place, people will get a better understanding of their health and how to manage it with more confidence. easyhealth.org.uk is an innovative website and a unique tool designed to help people to take more control of their health.

By Spring next year, easyhealth.org.uk will:

- hold a diverse range of more easy-to-understand health information (most of which will be downloadable for free) covering subjects from from ‘periods’ and ‘checking your testicles’ to medicinal information
- carry short films where people with learning disabilities visit a health professional
- have a mini photographic ‘library’ for inspiration on how to keep fit and well
- show accessible information for people with mild to moderate learning disabilities on knowing how to complain and knowing their rights
- be a resource of health information for parents and health professionals on: person-centred planning, health action planning, publications, top tips for consultations, direct payments, GP and hospital information
- link to other useful websites

Generate has aimed to make easyhealth.org.uk easy to use for as many people as possible (whether they are health workers or people with mild learning disabilities). The website has:

- sound (narrated by someone with learning disabilities)
- text that can be increased in size
- text that is simple, concise and friendly
- films (starring people with learning disabilities)
- photographs/ illustrations / leaflets

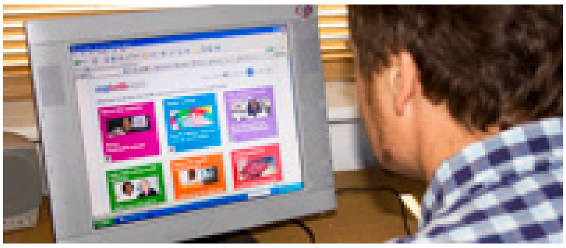
The website, although it is still being developed, has received very positive feedback from a range of organisations such as The Valuing People Support Team, NHS Direct, NHS Choices, The Elfrida Society, MENCAP, People First (London):

'Promote the website because it is really good and meets a real need!' People First (London)

'Excellent - good information and health advice. Unlike other websites that are either for people with learning difficulties or without, this website is for both and it gets the balance right....It has a lot of information but information you can understand.' Generate members consultation group

'Generally an excellent idea...the videos are an excellent idea...the consultation tips are good!...Overall it's great to see that people with a learning disability have been so closely involved in building the site.' MENCAP

'The website is clean, cheerful and easy to navigate' 'Know what I mean'



Generate has involved health professionals and people with learning disabilities in depth throughout the creation of the easyhealth website.

However, it is important to note that Generate has consulted with very few people who work with people with complex and profound disabilities. Generate would like to consider the needs of this group of people, so if you have any ideas about how the website might be improved, or if you have any content to put on it, please contact Jo at jo.giles@generate-uk.org

If you would like to look at the website, please contact Jo and she will give you a password.

Furthering the welfare of children with intellectual disability – a medical team's perspective

Evguenia Galinskaya
(final year) Medical Student, University of Cambridge

This Essay was short listed for the Royal School of Medicines forum on Intellectual Disabilities Students' prize.

Introduction

Several questions must be addressed by the medical team setting out to further the welfare of children with learning disabilities and complex needs. How can we decide what is in the best interest of a child who cannot communicate in a meaningful way and whose fragile health is expected to deteriorate soon? Should we use all available technology for aggressive, often painful, treatment that might prolong life by some months, or may it be that furthering the welfare of this child is simply about keeping her comfortable?

AJ's life: a vignette

Let us consider these questions through the needs of an individual child, AJ, a 12-year-old girl with profound multiple learning disabilities (PMLD). She has never been able to communicate in any way other than vocalizing to attract attention. She was born at term after uncomplicated pregnancy, but problems with development became evident when she failed to smile at four months. Multiple investigations revealed she was blind. Subsequently she developed epileptic seizures from seven months of age, though all blood tests and brain scans were apparently normal. Several differential diagnoses were ruled out, notably cerebral palsy, genetic and metabolic diseases. No definitive cause of AJ's PMLD has been found to date.

Unable to cope with the news of AJ's disabilities, her father left the family. She now relies on her mother for all aspects of care. AJ often needs sedation to stop agitation, as well as restraint to prevent unintentional self-harm by arm-biting. She is gastrostomy-fed and double incontinent. AJ comes to hospital with chest infections nearly every month for up to two weeks. She has required ventilation during the past five years and has had multiple pneumothoracies.

The medical team finds it increasingly difficult to communicate with AJ's mother who constantly "demands" investigations, therapies and specialists' opinions, which are not always thought to be in the best interest of AJ. The medical team agree that AJ will inevitably deteriorate in the next three to five years, potentially necessitating admission to the paediatric intensive care unit (PICU) due to respiratory failure or status epilepticus. Her medical condition is currently stable, and between hospital admissions she is managed well in the community. With regards to AJ's ongoing care and in the light of anticipated low life expectancy, the hospital staff have consistent feelings that the time will soon come when they will be unable to satisfy every demand of AJ's mother, and therefore they should begin communicating with her about what options are available should AJ become critically ill.

Medical, ethical and legal issues

AJ's case poses a great multitude of ethical dilemmas. Is there much scope for furthering her welfare through optimisation of appropriate treatment at the right time? I would like specifically to explore a hypothetical situation when the medical team may be reluctant to provide intensive treatment to AJ. The main difficulty in the clinical decision-making arises from the fact that AJ does not have a definitive diagnosis and so a prognosis is not easy to make. In the context of complicated ethical and legal issues surrounding AJ, it is crucial for the medical team to appreciate her as a whole, as well as through her mother's views, before making any decisions regarding her care. The *Four Principles* suggested by Beauchamp and Childress (1994) are generally accepted as an adequate framework for moral deliberation in health care and may help to resolve the moral problems posed by this case. I will consider each in turn.

A. Considering AJ's autonomy: AJ lacks competence and her mother acts as her proxy both legally and morally, guided by the standard of *best interest*. Respecting her mother's views is obviously important, but to avoid unnecessary uncomfortable procedures, the clinical judgement should be guided by what is considered to be in AJ's best interests, as stated by the General Medical Council (2006).

B. ***Beneficence:*** Strictly speaking, parents cannot demand procedures just because they are available. The health care team must evaluate the likely benefits versus burdens in each case and accept that this balance may change during ongoing care.

C. Non-maleficence: AJ lacks the capacity to comprehend the nature of invasive procedures. To prevent her from interfering with treatment, AJ is often restrained mechanically and pharmacologically, which may add to her agitation, discomfort and suffering. It is not unreasonable to think that in such situations she suffers more than a cooperative 12 year-old child without learning disabilities undergoing the same procedure. It is therefore important to acknowledge the mother's desire to explore all possible options, yet tactfully suggest that abstaining from invasive procedures may ultimately result in as desirable an outcome.

D. Justice: Should the society invest resources in the costly care of severely disabled children who may be considered unable to contribute to the wider community? It seems unthinkable that AJ should be denied treatment in a PICU simply on grounds of her disability and anticipated short life expectancy. In reality, there are often a handful of such beds available across the UK at any one time, so the decisions about their allocation are critical and are based on the likelihood of subsequent recovery. It is the duty of a doctor to maintain an open dialogue with the mother *before* events happen to avoid her feeling deceived under the NHS provisions.

Clinical goal-setting, decision-making and implementation

Good medical practice in paediatrics *"demands particular attention to communication and effective relationships with the patient's family"* (Royal College of Paediatrics and Child Health, 2002), ultimately contributing to the overall welfare of the child. Since the health professionals sometimes find it difficult to have a constructive dialogue with AJ's mother, it is vital to remain patient to facilitate effective communication for mutually acceptable goalsetting. Should the situation escalate, it may be even harder to communicate with her mother whose judgement may be impaired by emotions, frustration and irrational thoughts. It is therefore crucial to discuss in a non-threatening environment and in great detail all options potentially available to AJ in a crisis and establish how acceptable each of them is to her mother. Such conversations should take place over several consultations while AJ is relatively well. It is important to allow the mother to ask questions and understand the reasons behind any proposals so that she does not feel that some test or treatment is denied to her daughter because she is assumed to be less worthy.

According to the Royal College of Paediatrics and Child Health (2002), there are five circumstances in which withholding/withdrawal of life support may be considered in children: brain death, permanent vegetative state (PVS), "no chance", "no purpose," and "unbearable". AJ is neither "brain dead", nor in PVS. She is conscious. She successfully survived two previous admissions to PICU and would probably have a reasonable chance of survival next time. There is a problem with the "no purpose" or "unbearable" concepts, as for many parents their disabled child's life does have a quality and therefore purpose, so they may disagree with these reasons for not resuscitating. This is illustrated well by a controversial case of David Glass, a 12-year-old boy with spastic quadriplegia, blindness and PMLD (Dyer, 2007). The doctors decided not to escalate to extraordinary care, instead keeping him comfortable on diamorphine, which was against his mother's wishes. The medical team was probably guided by the "no purpose" or "unbearable" recommendations to withhold life-saving treatment from David. The European Court of Human Rights later ruled that "the decision to impose treatment on David in defiance of his mother's objections gave rise to an interference with his right to respect for his private life."

The way forward

In an event when the differences in opinions between the medical team and the parents cannot be resolved by an open dialogue, a family conference should be held bringing together the issues that would then go to the hospital ethics committee for consultation. Courts should really be the last resort, because they can be damaging for all parties involved.

The hospice and community paediatric teams involved in AJ's care helped her mother to appreciate that the management in the community can be very effective in preventing institutionalisation. The dialogue with the mother continues regarding the suitability of treatment escalation in a critical situation, or whether instead to focus on symptom control in a non-intensive setting. I think that careful forward thinking and a sensitive approach to AJ's mother may eventually result in a *positive decision* not to admit AJ to PICU next time she is critically ill.

It is also worth noting that assessing AJ when she is unwell on the ward may not always provide a reliable ground for clinical decision-making. Until I saw AJ in a "well" state, clearly enjoying simple activities at her special school, I was unsure why her mother insisted AJ does have a reasonable quality of life. It is therefore important not to underestimate the quality of life that parents describe when asking doctors for additional interventions to improve or at least maintain it. Gentle ongoing questioning of AJ's mother may help to monitor the balance of *benefits versus burdens*, assisting effective planning and implementation of AJ's management plan. Such trusting two-way relationship ensures that AJ's best interests are appreciated by all parties and catered for as fully as possible.

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PAMIS Healthy Lifestyles Project: Supporting Healthy Lifestyles for people with profound and multiple learning disabilities and their carers

Brenda Garrard
Development worker, Healthy Lifestyles Project, Fife, Scotland

This 3 year project run by *PAMIS* brings together good practice and research on improving the health of people with profound and multiple learning disabilities (PMLD) and their carers in order to enhance the quality of health in this disadvantaged group. The project is funded by a grant from the Big Lottery Fund, with complementary funding from six statutory agencies across Scotland. The project is being delivered to families with input from health, local authorities and *PAMIS*. A team of Project Development Workers were appointed to set up and deliver the programme of work in the six areas of Scotland where the project operates.

Over the three years (now into year two) the project is running a series of training workshops for carers on a wide range of health related topics. These are complemented by a parallel programme of community based leisure activities that have obvious health benefits. The workshops and leisure based activities respond to the recommendations highlighted in the NHS Scotland Health Needs Assessment Report of people with learning disabilities (NHS Health Scotland 2004). By promoting activities that allow access to the outdoors and increased physical movement and exercise, the poor physical, psychological and emotional well-being of people with learning disability can be addressed (Hogg 1992) and by improving access to good health care delivery, particularly primary health services, and training for family and front line staff can have a significant impact on the health of the person with PMLD (Hogg, 2001). The project is being conducted in Aberdeen city, Aberdeenshire, Angus, City of Dundee, Fife, Greater Glasgow, Perth & Kinross and South Lanarkshire.

Training Workshop Programme

Individuals with PMLD have very complex health problems. As a result of their long-term caring roles, the health of their prime carers is also affected. *“Current policies and increasing longevity are leading to a lifetime of care giving, limiting aspirations for self-realisation with apparently damaging consequences for the health of carers”* (Lancioni and O’Reilly 1998). The training workshop programme covers the principal health difficulties of both the individual and their parent/ carer. These are noted in Figure 1 on page 16.

All the workshops from year one have been completed successfully and we are now working on year two. For example, physical management awareness workshops involving two or three days of informative awareness training have already had a very positive impact on families. The physical demands of positioning, transferring and lifting a person are usually extreme. However, through dissemination of knowledge and practical skills carers are now more able to perform lifting in as safe an environment as possible.

Evaluation

Information has been collected on the health of the person with PMLD using the *Rochester Health Survey* (Janicki and Davidson 1999) and that of their parents/carers using the *General Health Questionnaire – 12* (Goldberg 1978). Results from these questionnaires will be used to monitor changes in health throughout the lifetime of the project the impact of the individual workshops and the leisure activities will be evaluated using structured questionnaires.

Leisure Activities Programme

The intervention programme of leisure activities that is anticipated to be beneficial to both the individual’s health and that of the carer is being run alongside the workshop programme on health topics. As previously noted, gaining access to physical activity can help the overall well-being of the person with profound and multiple learning disabilities and their family members/carers. Being outdoors also allows exposure to sunlight which increases the body’s absorption of vitamin D. Many people with learning disabilities have been identified as deficient in vitamin D due to limited outdoor access and also due to the lack of adequate vitamin D content of the various diets used (Tohill and Laverty 2001). The topic of healthy eating is being addressed in the health care workshops being delivered as part of the overall project.

Examples of the types of leisure activities on offer include:

- Adapted Bike Rides
- Alexander Technique
- Equine Activities
- Hydrotherapy and Water Sports
- Music & Movement
- Wheel-chair based Exercise
- Tai Chi
- You & Me Yoga
- Wheelchair Ice-skating and wheelchair roller-blading
- SOMA – Sporting Opportunities for Motor Activities

Adapted bikes are already available to families in different regional parks in Scotland as a result of campaigning by *PAMIS*. Wheelchair ice-skating has also been enjoyed with families attending sessions held at Dundee and Kirkcaldy Ice-rinks and these have now been extended to Glasgow, Aberdeen city and Aberdeenshire.

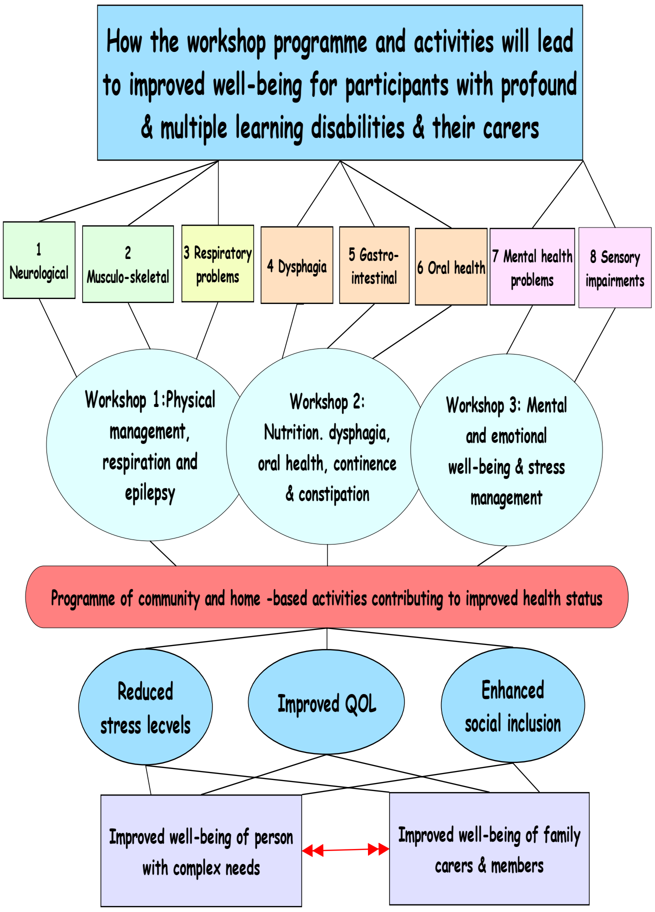

Figure 1 Health areas targeted in the Health Lifestyles Project and anticipated benefits.

Music workshops, fun/sensory walks and wheelchair dancing, have also been offered in different regions where the project operates. Sporting Opportunities for Motor Activities (SOMA) has been highly successful in Tayside with new groups starting in Aberdeenshire and Fife involved in planning future SOMA activities. Taster days on SOMA are also being held in the other areas with a view to them becoming integrated into local leisure activities programmes.

Overall the Healthy Lifestyles Project is running successfully and will continue to do so as *PAMIS*, in collaboration with the many professionals involved in delivering care to this vulnerable group endeavour to improve the lifestyles, health and wellbeing of people with learning disabilities and their carers. During the first year of the project, 264 family carers and 177 people with PMLD attended the health care training workshops. Additionally, 127 paid carers and 27 other professionals participated in them and 474 people with PMLD took part in the leisure activities programme.

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Listen up!

Laura Waite
Lecturer in Disability Studies, Liverpool Hope University

It has long been recognised that there is a higher than average incidence of hearing impairment in individuals with learning disabilities (McCracken 2002, National Deaf Children's Society, 2004, Picard, 2004); however, people with profound and multiple disabilities are much more likely to experience 'diagnostic overshadowing' (Outellette-Kunz *et al* 2004) with symptoms frequently being ascribed to the severity of their intellectual impairment.

Common causes of hearing impairment

Hearing impairment is generally categorised in four ways, and is largely related to the specific location within the hearing system that is not working as it typically should:

Conductive deafness – where sound cannot pass freely through the outer or middle ear.

For example:
- wax or a foreign body blocking the ear canal
- fluid in the middle ear cavity (glue ear)
- malformation or disconnection of the three bones
- perforation
- infection

Sensorineural deafness – where there has been damage to the cochlea in the inner ear or auditory nerve.

For example:
- heredity
- viruses, such as rubella and meningitis
- presbyacusis (age related hearing impairment when the hair cells that pick up the higher pitched sounds wear out)
- head injury

Mixed deafness – where there is sensorineural and conductive deafness present.

Auditory Processing Disorder – where there is damage to the part of the brain responsible for processing auditory information.

Does it matter?

Sadly, a significant proportion of people with profound and multiple disabilities will not have had their hearing impairment identified which according to Evenhuis and Nagtzaam (1998) is likely to have harmful effects on the social, cognitive, emotional and communicative development of an already disabled group. Furthermore they suggest that if an individual is not supported to manage their hearing impairment appropriately then their experience of intellectual impairment may be magnified or they may be at risk of developing behaviour difficulties.

But 'they' can't be tested!

There is a commonly held misconception that people with profound and multiple disabilities would not be able to comply with a hearing test. However, while they may present audiology clinics with some challenges, testing is not impossible, and indeed, the National Newborn Hearing Screening Programme which was introduced in 2001 provides evidence to counteract this argument.

In a typical situation a patient would have their hearing tested by sitting in a sound-proofed room, wearing a set of headphones and responding to a series of tones. For people with profound and multiple disabilities this test is unsuitable, however the following procedures are more likely to be appropriate:

Otoscopy – This is an examination of the ear canal and drum using a small torch like instrument and will reveal problems such as infection, blockages, perforations and fluid in the middle ear. If impacted wax is identified this will need removing with either drops, water jets (irrigation), suction, or surgical instruments.

Tympanometry – This is used to provide information about the middle ear. A probe is inserted into the ear canal for a few seconds and acoustic signals are presented. The instrument then provides a read out which will show up some common middle ear problems such as glue ear and damaged ossicles.

Otoacoustic Emissions – If the cochlea in the inner ear is functioning normally then it produces an internal echo as it processes sound. This echo can be measured which supplies information on the functioning of the cochlea and middle ear. It is performed in a similar way to typanometry above.

Brainstem Evoked Response Audiometry – It is necessary for the individual to be resting for this test so sedation is often recommended but it involves the application of electrodes to the head. A series of acoustic signals are then presented brain activity is measured.

Behavioural Observation Audiometry – This is when a sound is presented to the individual being tested and a behaviour is observed, for example increased movement, stilling, eye widening, glancing at sound source. The sounds presented may include speech, warble tones or pre-measured sound making toys (Maltby and Knight, 2000).

The real reasons why testing is tricky

As we can see there are a range of tests that are appropriate for people with profound and multiple disabilities; but these tests are only as good as the clinic providing them and the person assisting the individual with profound and multiple disabilities. It must be understood therefore that it is often the barriers we put up that result in poor experiences of hearing assessment. From a clinic point of view these barriers might include: excessive waiting times; physically inaccessible rooms; poor practitioner attitudes; inadequate appointment time. From the person assisting it might include: knowing little about the individual they are supposed to be supporting; carrying out insufficient preparatory work with the individual; not obtaining relevant medical information before the appointment.

Hospital staff can be quick to blame the support staff who accompany the individual and vice versa but the fact remains the barriers can be created by both sides and they all need to be addressed if a successful hearing assessment is to be carried out.

What if someone does have hearing impairment?

There is a range of things that we can do to support someone with hearing impairment. The following provides a general overview.

Hearing aids

Some audiologists may be reluctant to fit a hearing aid on an individual with profound and multiple disabilities either because they have misconceptions about the perceived benefits of amplification or because they have been unable to obtain ‘precision’ in their results of hearing levels at different frequencies. Given the potential impact that hearing impairment can have on the lives of people with profound and multiple disabilities, audiologists should be encouraged to undertake such intervention even if it means experimenting, for example starting with a small amount of amplification to the frequencies which the results suggest are most impaired and gradually increasing it over time whilst carefully monitoring its effects.

Cochlea implants

Cochlear implants consist of an array of electrodes surgically implanted into the cochlear in the inner ear. The criteria for obtaining one are fairly complex and recipients tend to be postlingually deafened adults or profoundly deaf children. However, more recently some cochlear implant teams have provided them to people with profound and multiple disabilities.

Acoustic Environment

While the use of amplification can be valuable for many individuals, even more so is a consideration for and/or modification of the acoustic environment that they are in. It is therefore essential that supporters take into account the following factors:

Background noise – Quieter environments are more likely to help people concentrate and use any residual hearing more effectively. It is therefore paramount that we do what we can to reduce noise from internal and external sources.

Lighting – When people experience hearing impairment they will be much more reliant on their vision. Therefore it is essential that there is good lighting so that people can pick up on visual clues.

Surfaces – Sound waves reflect off hard surfaces. Therefore, places like dining rooms with hard tables, plates and clanking cutlery can be a difficult environment for a person who has a hearing impairment, especially if they are hearing aid users. Soft furnishings absorb sound waves and can help, e.g. tablecloths, cushions and curtains.

Distractions and ‘visual clutter’ – Trying to interact with someone with a hearing impairment in a room with lots of distractions can be problematic. The person may find it difficult to concentrate on the conversation if there is too much going on around. If it is not possible to reduce the distractions, move somewhere else to continue the interaction.

Environmental equipment

Sadly some people often see little relevance in obtaining environmental equipment such as vibrating alarm clocks, flashing doorbells, amplified smoke detectors and loop systems for people who have profound and multiple disabilities but I would argue that they are as entitled to know their doorbell has rung as anyone. The local social services sensory impairment team will be able to offer advice around equipment.

Further support

Factsheets

There is a series of factsheets that are available to download free of charge from www.lookupinfo.org which will expand on some of the material covered throughout this chapter. Titles include:

- Identifying Hearing Impairment in People with Learning Disabilities
- Supporting People with Learning Disabilities with Hearing Assessment
- The Effects of Hearing Impairment on People with Learning Disabilities
- Ways to Help People with Learning Disabilities who have Hearing Impairment
- Hearing Aids and Environmental Equipment for People with Learning Disabilities

Special Interest Group

The National Special Interest Group on Hearing Impairment in People with Learning Disabilities is a group of professionals from across the UK who meet biannually. The professional backgrounds of the members vary but include: Learning Disability Nurses, Audiologists, Speech and Language Therapists and Hearing Therapists. Over the last decade the group has made a significant contribution to improving hearing care for people with learning disabilities by carrying out research, contributing to publications and developing resources. The group is an open forum and welcomes new members.

Further information can be sought from Laura Waite waitel@hope.ac.uk.

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About Children and Young People (0 - 25) with Disabilities / SEN

Note: You can receive the whole bulletin as an e-mail attachment if you request it by sending a message to p.limbrick@virgin.net. To view the lisitings www.icwhatsnew.com

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Us and Our Health

[Extract taken from the Executive Summary]

Sandra hill, Day Service Manager

'Us and Our Health' is an innovative project that was first developed to look at new ways to enable engagement with adults with learning disabilities to discuss how they see themselves and their health.

This project involved a number of organisations in the community ranging from colleges to theatres and the adults involved were from a number of day services across Worcestershire. The 'Us and Our Health' campaign capitalised on drama as a medium to ensure the project was inclusive and less intimidating for those adults that may struggle to portray their feelings.

Workshops were held over a three-month period at the Artrix theatre, in Bromsgrove. The end result was two shows that were extremely well attended by a range of organisations and professionals including but not limited to, health and education professionals, people from the adult and community care services, voluntary agencies, carers, friends and family.

In addition to the performance, material was filmed from the weekly preparation sessions and was used to create a DVD. This film was designed to raise awareness and promote discussion around health inequalities faced by adults with learning disabilities. This DVD can now be used as an excellent example for training purposes of a project that involved the community and addressed the issue of social exclusion of adults with learning disabilities. Due to this project's success, another campaign entitled 'Us and our education' is planned for 2008.

Background

This project began two years ago when a group of people with learning disabilities had taken part in a series of workshops with a local theatre company where they performed and filmed "All About Us" using mime, movement and dance as a medium to convey the story. What was surprising was that this group of individuals with very little communication skills managed to come together to make a film that illustrated their thoughts and feelings.

This group of adults enjoyed the experience so much that it was recognised as an excellent method to involve and engage people with learning disabilities. Therefore in Spring/Summer 2006 the search began to find a theatre company who could support people with learning disabilities to speak out about real issues that affected them.

The 'Women and Theatre' Group had a vast amount of experience working with minority group. This experience enabled the group to work at its own pace and at a level where the adults felt completely included and treated as equals.

One of the areas that was particularly pertinent and had large press coverage in the national press at the time of the project, focused on health inequalities for people with mental health issues and learning disabilities. Alongside this coverage, the 'Valuing People' task group had also highlighted the need for health to be high on the agenda for those offering services to people with learning disabilities.

After sending a promotional leaflet to a number of learning disability day services across the county, it was tremendously exciting to see that twenty-seven adults with learning disabilities wanted to participate in three taster sessions and complete a performance at the end of the program.

The local college was approached to see if their students might want to get involved too. The performing arts students from North East Worcestershire College were delighted at being invited to get involved in our community theatre and were happy to work at helping and engaging with vulnerable groups.

Aims, objectives and key achievements

The main objectives were for people with learning disabilities to take part in drama workshops, speak out and be consulted about things that are important to them and more importantly, to have fun whilst taking part.

It was really a project about getting a number of people from different backgrounds and circumstances to come together to achieve a common goal. The community spirit surrounding this project was outstanding. To work as an inclusive group with no social exclusion was the biggest aim. It was great to see people with disabilities working alongside non-disabled young people on an equal footing-supporting each other and learning together.

The main outcomes of the project were two very successful performances that illustrated the group's feelings about themselves and their health concerns and the production of a DVD, which has been used to inform students and professionals within health and social care about real issues for people with learning disabilities.

Paula Bullock, who attends Padstone Day Service and took part in the project said,

"It was good fun to do. I would like to do more drama"

The DVD highlights issues around:

- Giving people with learning disabilities a voice
- Giving people the ability to talk about themselves and their health issues
- The inequalities around health issues for people with a learning disability.

There was a learning curve for all parties involved in the project, particularly for the performing arts students who had not had experience of working with people with learning disabilities. By the end of the twelve weeks they had made great friendships with the group and they were mutually supporting each other in equal partnership.

Evidence of success

The final result of the workshops was a full audience for both performances that included a wide range of people including local councillors, the Mayor of Bromsgrove, Vice Principal of the local further education college and Senior Health, Education and Learning Disability managers.

Feedback from the audience was extremely positive. The post show discussions with the audience promoted health and at times included very poignant discussions surrounding the lives of people with learning disability and feedback about what people had witnessed.

"The performance was highly professional, emotional, very entertaining and extremely informative. There was a wonderful reaction from the audience at the end and it was certainly one of the best pieces of `issue-based theatre` I have ever had the privilege to see". Mike McCarthy, Vice Principal, North East Worcestershire College

The greatest success comes from the adults for whom this project was dedicated. The adults who took part in the workshops and performances have stated that they want more opportunities like the 'Us and our health' campaign to speak up about their own lives, to have fun and to be involved with something real and meaningful.

There has also been a request from the principal of North East Worcestershire College to put on another series of workshops entitled 'Us and Our Education' due to the success of this project.

Partner Involvement

We had a great response to this project and a number of organisations took part each contributing something different.

Women and Theatre

The Women and Theatre group has 23 years of experience creating illuminating new work on subjects that really matter to people. They have pioneered a unique process for devising projects from in depth research. The main aspect of these projects is for people to share stories with communities in a respectful and participatory process. The resulting drama is both funny and moving because it connects with people's real life experiences. Their work provides an interactive forum through which to deepen understanding and facilitate change. They deliver diverse drama activity in real settings.

This group frequently work with those minority groups at the fringe of society who are often excluded. It was great to have them onboard for the 'Us and our health' campaign so that we could really connect with our residents.

"Our experience of delivering the Us and Our Health project in partnership with Worcestershire`s Learning Disability Services and NEW College represented one of the most productive and genuine examples of partnership working to date. The project was a huge success with a lasting legacy of links made between the day centres, the college and ourselves, with prospect of further partnerships in the future. We were able to produce an engaging theatre production and awareness raising DVD which promoted discussion around health inequalities faced by adults with learning disabilities and had the power to affect change." Jess Williams, 'Women and Theatre'.

Theatre and the Community at North East Worcestershire College

This foundation degree is a partnership arrangement between the University College of Worcester and North East Worcestershire College with input from local employers. The course breaks away from traditional theatre training models, offering an alternative way to train for a career in the performing arts.

Fundamental to the foundation degree is the creation of strong community partnerships. The partnership approach enables students to benefit from work experience, whilst also broadening the scope of their experience of wider social issues and helps bring diverse groups of people within the community together.

Worcestershire County Council Learning Disability Services

Learning Disability Services in Worcestershire are provided through an integrated service. This consists of a partnership between Adult and Community Services and the Worcestershire Mental Health Partnership.

Learning Disability Services have been working towards the Government's 'Valuing People' principles and much has been achieved over the past few years in modernising the services that are offered to people with Learning Disabilities. People with learning disabilities are becoming more empowered to speak up about what they want. This is a gradual process but people are becoming more involved and consulted about being active citizens involved within their own communities.

We cannot do these things in isolation and the work we have achieved together with Women and Theatre and North East Worcestershire College has been extremely rewarding for everyone involved.

Artrix Theatre

The ability to use the state of the art facilities at the Artrix Theatre, a local community theatre in Bromsgrove was fantastic and crucial to the success of this project. The theatre allowed weekly use of the drama studio, the theatre for rehearsals and performances and the film-editing suite.

Conclusion

'Us and Our Health' has provided an opportunity for social inclusion with a project that the whole community could engage with. It was great to see people with learning disabilities as active citizens and involved with real issues within the community.

Worcestershire County Council conducted true consultation and listened to what our residents had to say. With a person centred approach we focused on a project that would engage with the community.

Partnership working provided a win/win situation, with each arm of the partnership meeting their own individual targets and together achieving the main aims and objectives of the project. The project showed real synergy within the team.

It was an exceptional opportunity for the college students to understand and accept people with learning disabilities as valued team members.

The DVD is available as a training tool, which will be invaluable to students and professionals within the field of health and social care in highlighting not only health issues but also the discrimination that people with learning disabilities face on a day-to-day basis whilst trying to live within their own communities.

For more information or a full version of the Project Executive Summary contact the Project Coordinators:

Sandra Hill Day Service Manager,
shill@worcestershire.gov.ukk
Adult and Community Services, Worcestershire County Council

Jacqueline McGonagle,
jmcgonagle@ne-worcs.ac.uk
Course Leader for Foundation and Theatre in the Community, North East Worcestershire College.

Jess Williams,
jesswilliams@womenandtheatre.co.uk
General Manager, Women and Theatre

The UK Health and Learning Disability Network

The UK Health & Learning Disability Network is hosted by the Foundation for People with Learning Disabilities (FPLD) and sponsored by the Valuing People Support Team with subscriptions from Welsh and Irish contacts.

The Network currently offers:

- moderated electronic networking; currently around 1,700 members drawn from a wide variety of backgrounds (family carers, primary care, learning disability services and other mainstream health services)
- searchable archives.
- expert input from Janet Cobb, who is an associate consultant with FPLD and a very experienced practitioner with unrivalled knowledge of who is doing what and where good practice can be found.
- four network meetings a year that include interesting presentations and ample opportunity for face to face networking

The network membership is regularly contacted by DH and other organizations in relation to consultations and information in relation to people with a learning disability and health issues.

Membership of the network is free and an open invitation is extended to anyone with an interest in health issues and people with a learning disability.

To join the network log onto:
www.jan-net.co.uk
or www.learningdisabilities.org.uk/ldhn
and complete the electronic joining form.

For more information and any queries contact
Janet Cobb
jcobb@fpld.org.uk or janet@jan-net.co.uk

Future Focus

Families

Beverley Dawkins

The next edition of PMLD Link will focus on families

We would especially like to hear from you if someone with profound and multiple learning disabilities is a member of your family, whether you are their parent, grandparent, sibling or other relative, we would welcome your perspective: What helps make family life work for you? What challenges you? Are there any particular issues you would like to see this publication cover? Even if writing an article is something you just don't have time for let me know what you would like to read about in this next edition and I will do my best to include it.

We would also like to hear from you if you are provide a project or service that supports families of children or adults with profound and multiple learning disabilities. Tell us why and how you set it up, what things you needed to take in to account to really ensure it meets the needs of the children or adults with profound and multiple learning disabilities who are using it.

Please send your ideas and articles to me by 6th March at Mencap:
beverley.dawkins@mencap.org.uk

Beverley Dawkins

Beverley Dawkins
National officer for profound and multiple learning disabilities

REPORT BACK

Multisensory environments big & small: validating current practice

October 2007, London.

A one day multisensory forum - sharing knowledge, experience and innovation.

Thanks to nearly 100 delegates who attended the conference, the day was a great success and a special 'thank you' to all our speakers. The venue and food were great and, more importantly, the speakers were fantastic. This year's first 'Sensory Exploration Conference' went so well, we will be doing it all again next year!

Paul Pagliano gave us the academic focus for the conference. Paul shared his ideas about assessment and evidence based research.

Robert Orr was as entertaining as always! His basic non technical and direct approach to 'sensory without technology' was inspirational. Roberts Book 'My Right To Play' is a must read!

Mike Ayres shared his in-depth knowledge about design and his wonderful talk was accompanied by a beautiful 'textures' slide show.

Alan Black gave us the head teachers 'no nonsense' advice on purchasing! He showed us the Beatrice Tate School studio, which has been a revelation in special education.

Gill Kennard demonstrated specific signs for the multi sensory room from the 'Signalong' vocabulary. Everybody had a go!

Richard Hirstwood did a short video presentation about the development of the multi sensory room.

Flo Longhorn talked about the brain and the reason why we need multi sensory approaches.

Alison Shorrock outlined the wonderful 'Space Centre' in Preston and shared her good practice.

Susan Fowler Susan's fantastic dvd presentation, sadly was not available to show due to the industrial action by Royal Mail.

Thanks to Flo Longhorn for this inspiring feedback!
For more info visit http://www.multi-sensory-room.co.uk

NEWS

"Death by indifference" - update

In March, Mencap published 'Death by indifference', a report that used the stories of six people with a learning disability who died in NHS care to show how the health service is failing people with a learning disability.

Mencap believe people with a learning disability face institutional discrimination in the NHS. This is because

- The lives of people with a learning disability are often not valued by health professionals. Comments such as 'wouldn't it be better for everyone if we let him go' are all to common
- There is a failure to communicate with people with a learning disability, especially people who are non-verbal.
- Diagnostic overshadowing, where medical symptoms are dismissed as a behavioural part of a person's disability, resulting in a potentially dangerous delay in diagnosis.

All these factors appear in Tom's Story

Tom was just 20 years old when he died. His parents became concerned that he was in pain. Although Tom couldn't talk, he could communicate. His parents noticed that his behaviour was changing – he was gouging and scratching his head to show his distress.

Tom's Mum and Dad were worried and repeatedly asked for the reason for his pain and distress to be looked at by doctors. He was sent to a consultant doctor, who suggested his pain was due to problems with his digestive system, and this should be investigated. But the advice of this doctor was not followed, and Tom's parents continued to watch their son deteriorate.

Eventually staff in Tom's new residential home listened to his Mum and Dad, and he was taken to hospital. They found he had an ulcerated oesophagus, but by this time it was too late for Tom and he died before doctors could help him.

Death by indifference was one in a long line of reports highlighting the unequal healthcare the people with a learning disability receive. However, the bravery of the families in sharing the stories of their loved ones gave a face to the discrimination that was impossible to ignore. A large amount of media coverage pushed the Department of Health to take action, and on the day of the launch, they agreed to establish an independent inquiry into the health treatment of people with a learning disability, learning the lessons from the six cases that appear in the report.

Health minister Ivan Lewis admitted there was **"systemic indifference"** towards people with a learning disability in the NHS, and Alan Johnson, Secretary of State for Health, admitted **"people with learning disabilities face some of the greatest health inequalities"**.

The independent inquiry is now underway, chaired by Sir Jonathan Michael. At the same time, the health ombudsman is investigating the six deaths in the report, with the hope that the families will finally have the answers they have been searching for. The these findings are planned to be made available to the independent inquiry panel.

The independent inquiry is planning to release its recommendations in June of next year. But before then, action is being taken by some. Health professionals across the county are responding to the report by examining their practice, and using the information for training and better practice. The hope is that these pockets of good practice will spread to the whole of the NHS.

It will take a firm lead from the Department of Health before the better treatment of people with a learning disability is imbedded into the culture of the NHS, and so far there has been limited action from them. Annual health checks are yet to be introduced, training in learning disability is still minimal for non-specialist staff, and the confidential inquiry into premature deaths of people with a learning disability has been shelved.

The independent inquiry recommendations need to have teeth to bring about the change so desperately needed in the NHS, and Mencap will continue to campaign to make equal treatment a reality for all people with a learning disability using the NHS.

For further information contact:
Hannah Rutter, Campaigns Officer
Tel: 020 7696 6918
Email: Hannah.rutter@mencap.org,uk

PMLD-Link achieves Registered Charity Status!

PMLD-Link achieves Registered Charity Status!

After what seems like months, if not years, of negotiating PMLD-Link is now a Charity. All members of the editorial team agreed that this was a very desirable goal as it would open up a number of benefits which we hope will lead to greater financial stability, and therefore more likelihood that the journal will survive into the future.

Although the number of subscribers is small, we believe that the readership is much larger as many of the subscribers are organizations which provide education, social service support, or other services designed to promote the wellbeing of people with PMLD. We know that we have a faithful core of subscribers who have been getting PMLD-Link for many years while others come and go in a relatively short time. This means that the finances available just cover the physical costs of production and mailing but cannot now cover costs of administration and we need to raise funds urgently not just to keep going but also to develop further. Hopefully, now that PMLD-Link is a charity we can tap into many more sources of financial support. We have now been registered for Gift Aid (form enclosed and on p35) and this will add a significant amount to our subscription income from individual subscribers. As you will see from the form, the amount we can claim is reduced in April 2008 so please, send in your subscriptions before the 5th April date so that we can gain the maximum benefit in this first year of being a charity.

We have many plans for development of PMLD-Link in the future, but our first bids for funding will focus on setting up a website which we hope will both be useful and also attract more subscribers. Eventually we would like to make PMLD-Link available electronically, but this is some way down the line yet. We would like to develop in ways that are useful to our readers and will need to know what you think is good, what less good, what else you would like to see in PMLD-Link. In order to support our funding applications we are gathering evidence of who reads PMLD-Link and how they feel about it. We shall soon be sending out a questionnaire and it would be really helpful if you could fill it in and send it back to us. It should take very little time to do, and will be a way for all our readers to help in keeping PMLD-Link going as well as letting us know how we can make it better.

Stars at the Harbour
A sensory Learning Experience

The 'Stars at the harbour' pack can be used in many ways. It focuses on the mathematical concept of the star shape through different stars found at the harbour and seaside. Each song focuses on a different aspect of the star shape. For example, the first song, the captain's song, uses as its focus the star on the cap of a captain of a ship. There is an audio link at the bottom of the page to sample a section of this song. The starry picnic song uses star shaped food as focus, whilst the flag rap looks at all the countries with stars on their flags. There are 8 different songs.

The DVD lasts for 30 minutes and runs continuously, though the DVD is sectioned into tracks so that you can select one part of the programme if you wish. The songs are linked by 30 seconds of music to give you time to change props or position.

Available from Sensabout (www.sensabout.com)
Mrs Liz Haslam,
Sensabout,
5 Ash Close,
Tarporley,
Cheshire,
CW6 0TY

Happy Birthday Changing Places!

Changing Places, Changing Lives was launched a year ago to campaign for Changing Places toilets – which include a hoist, changing bench and plenty of space – to be installed in all big public places in the UK.

Changing Places toilets are needed by people with profound and multiple learning disabilities, their families and carers, and other people who need assistance to use the toilet. Without Changing Places toilets thousands of disabled people and their families have to return home after a few short hours, or are forced to carry out changing on dirty toilet floors.

The Changing Places campaign is changing this. Since the campaign launched at the Tate Modern in July 2006:

- the number of public Changing Places toilets on our UK map has increased from eight to 32
- 30 venues have committed to install a Changing Places toilet in the near future
- plans to install Changing Places toilets in Asda supermarkets and other key venues are being developed
- eight venues with Changing Places toilets won a 'Loo of the Year' award, and Nottingham City Council also won a national Community Care Award
- significant progress has been made to secure a change to British Standard 8300 (which gives recommendations for the design of new buildings to meet the needs of disabled people) to include Changing Places toilets
- an Early Day motion in support of the campaign tabled by Philip Davies MP was signed by 112 MPs of all parties
- over 1.5 million people have seen media coverage of the Changing Places campaign
- a fact sheet on the legal issues associated with Changing Places toilets has been produced by the Changing Places consortium, together with experts in law and disability and moving and handling policies.

The incredible support and hard work of campaigners up and down the country has greatly contributed to this success. Many campaign groups have formed and are making significant progress locally. In particular, local efforts in Bradford have led to the opening of seven Changing Places toilets with plans for more in the pipeline, and mums Julie and Alison have been successful in getting Changing Places toilets installed in their local shopping centres.

All this means real changes to the lives of families who had previously struggled to leave the house. As one family explains *"We can now enjoy a day out just like anyone else".*

But there is still so much more to be done to achieve our goal of having a Changing Places toilet in all big public places across the UK. If you would like to get involved you can:

- Visit www.changing-places.org
- Get our local campaign pack www.changing-places.org/get_involved.asp
- Tell us if you know of a Changing Places toilet or plans to install a Changing Places toilet so we can add it to our map: email changingplaces@mencap.org.uk tel 020 7696 6019
- Join our web group to keep up-to-date with the campaign www.changing-places.org/get_involved_emailgroup.asp

Joint Committee on Human Rights inquiry into the human rights of adults with learning disabilities

A summary of the submission on behalf of the PMLD Network by Beverley Dawkins (Mencap)

The PMLD Network have submitted evidence regarding the unmet needs of people with profound and multiple learning disabilities to the *Joint Committee on Human Rights Inquiry into the human rights of adults with learning disabilities,* and advised on recommendations for change.

The need for better planning:

People with profound and multiple learning disabilities have been described as the invisible minority. Local authorities do not collect specific data on people with profound and multiple learning disabilities but it is clear the numbers are rising and there is a lack of planning for their needs.
Services are by no means seamless as young people move from child to adult services. Parents often feel like they are falling into a black hole.

The need to challenge attitudes and values:

One of the greatest barriers that people with profound and multiple learning disabilities face is the negative attitudes of others. Judgements are made about the meaning and quality of people's lives.
It is important that everyone understands that people with profound and multiple learning disabilities have the same rights as every other citizen and that their lives should go beyond being cared for to being valued for who they are as citizens.

The need for better family carers support:

Mencap's *No ordinary life* report found that few families were satisfied with the care support services they were receiving.
The caring task associated with someone with profound and multiple learning disabilities is both highly intensive and long lasting. In particular parents felt dissatisfied with the assessment processes. They felt assessments were not thorough enough, not reviewed frequently enough and failed to deliver what they needed.
Mencap's 2006 report *Breaking Point* found that 7 out of 10 families have reached or come close to breaking point because of a lack of short break services.

The need for better healthcare:

People with profound and multiple learning disabilities may have a wide range of health needs. An increasing number of people are technology dependent. However access to mainstream healthcare is poor as many health professionals are ill equipped to meet the needs of people with profound and multiple learning disabilities.

- There is growing concern that adults who have had regular access to physiotherapy, hydrotherapy and postural care have limited support once leaving school.
- Optometrists are not given enough money to test people people with profound and multiple learning disabilities and so needs are often not picked up.
- For people who may not be able to communicate their symptoms easily it is important to develop ways to recognise and manage pain.
- Introducing annual health checks and health action plans is crucial to ensure each person is able to achieve the best possible health they can.

The need for greater representation:
The learning disability task force, partnership boards, the national forum, regional forums and the majority of advocacy groups are not representative of people with profound and multiple learning disabilities. This means their needs remain low on the government agenda.
One survey showed that only 11% of advocacy schemes could support someone with profound and multiple learning disabilities. Most will not use formal communication such as speech or sign language yet they are largely surrounded by a workforce that is not trained to understand their communication method.

The need to remove barriers:
The physical barriers facing people with profound and multiple learning disabilities include manual handling practice and the lack of fully accessible toilets.

Manual handling:
Many authorities have imposed blanket bans on manual handling which restricts the access of many people to the community. For some people not all lifting can be done mechanically and so they cannot access services at all.

Fully accessible toilets:
Another major barrier is the serious lack of adult sized changing facilities. Standard accessible toilets meet the needs of many people with disabilities but not all.

In July 2006 the Changing Places consortium launched the Changing Places, Changing lives campaign for changing places toilets which include an adult sized changing bench, a hoist and enough space for two carers.

The need for better support:

Ultimately we cannot change the nature of people's disabilities. We need to understand the specific needs of people with profound and multiple learning disabilities in order to ensure that the right support is in place.
Some well intentioned initiatives actually further disadvantage some people. One example of this is the modernisation of day services. Often community involvement provision does not have the equipment or the staff training to support complex physical and health needs.
People with profound and multiple learning disabilities have the right to access their community like everyone else. This means staff training, specialist facilities in the community, more accessible transport and imaginative and meaningful use of the community.

The need for equality of opportunity:

The lack of real choice over where and with whom people live is another example of the high level of discrimination faced by people with profound and multiple learning disabilities.
Individual budgets are an example of an innovative model of support however there remains very few examples where someone who needs very high levels of support has been offered this alternative.

Action Points:

- Undertake research into the numbers of people with profound and multiple learning disabilities.
- Provide education around the meaning and quality of people's lives.
- Set a minimum short breaks entitlement
- Train healthcare staff in the rights and communication needs of people with profound and multiple learning disabilities.
- Provide an advocate for all people with profound and multiple learning disabilities.
- Re-think manual handling policies.
- Introduce mandatory planning of fully accessible toilets into all new planned public buildings.
- Introduce the needs of all into staff training and innovative service provision.
- Provide fully supported housing for all adults with profound and multiple learning disabilities.

Please contact Bella Travis, bella.travis@mencap.org.uk for the full version of the submission.

Palliative Care Ambassador for ACT

ACT, the UK charity which represents children with life-limiting or life-threatening conditions and their families, has named Rosa Monckton as its new Ambassador for Children's Palliative Care. Rosa Monckton, will play a key role in helping ACT champion their aim to ensure that all children and young people with life-limiting conditions receive the best possible quality of life and care. Rosa will be supporting ACT to raise awareness of these children and their family's needs, and to campaign for better policies to support them and realistic funding to provide every child with the services and care they deserve. Rosa said:

"***When ACT first asked me to become an Ambassador I was humbled, and delighted. Delighted because it is an obvious place for me to sit. I have an interest in all children's palliative care, and ACT is the only UK umbrella organisation for all of these vulnerable children….I want to do my utmost to ensure that these vulnerable children and their families receive the best possible care, and that they are never forgotten. I promise that whatever I can do, I will."***

For information about ACT - www.act.org.uk
ACT Helpline 0845 108 2201

RESOURCES

The University of Birmingham Induction Pack on SLD/ PMLD

The University of Birmingham has developed an induction pack for staff new to working with children and another for those working with adults with severe and profound learning difficulties. Currently they are being trialled in 24 schools and 8 adults settings. The initial feedback is very encouraging and the packs should be finally ready in January 2008.

The packs are designed to be studied for one and a half hours per week for 20 weeks (30 hours). Half an hour is spent on reading and looking up information, half an hour is spent in discussion with a more experienced colleague and half an hour in collecting information when working with or observing children/ adults with learning difficulties and disabilities.

The pack covers an introduction to aspects of severe, and profound learning difficulties and disabilities that will enable staff to understand and meet fundamental needs related to communication, behaviour and learning.

Six aspects of working with children/ adults are covered.

1. Identifying Needs
2. Planning to Meet Needs
3. Meeting Needs
4. Communication
5. Behaviour
6. Working Together to Meet Needs

Participants will receive an attendance certificate on completion of the course and (if eligible) will also be encouraged to study further by applying for the University of Birmingham distance education certificate course ‘Learning Difficulties and Disabilities (Severe, Profound and Complex)’.

The course pack is only available in electronic form but it can be used on screen or downloaded as many times as required. Cost: £100 per organisation. The pack will be on sale from January 2008.

Further information from: Dr Penny Lacey (p.j.lacey@bham.ac.uk)

BEING PERSON CENTRED

This 20 minute film shows real staff working in real services talking about how they are trying to be more person centred and it is really useful for training new staff.

Part 1 explores what the Government’s White Paper ‘Valuing People’ means when it talks about choice, independence, rights and inclusion.

Part 2 show you examples of people working in a more person centred way, using different methods of communication and person centred approaches such as ‘Me and My Life’ and ‘This is My Life’.

People with PMLD are included in the illustrations and there is generally a very positive view of both those with PMLD and their supporters.

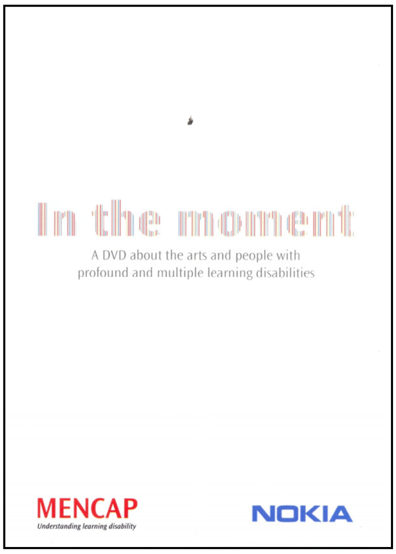
The DVD was made by Silva Productions for Worcestershire County Council, Solihull Primary Care Trust and Worcestershire Mental Health Partnership Trust. Copies can be obtained from Worcestershire County Council 0195 23368 or Solihull-Community Psychology Service 01564 771877.

Using interactive whiteboards

An excellent guide to using interactive whiteboards with pupils who have sensory impairments or physical disabilities.

This guide is by Vernon Webb, Teacher of Visually Impaired Children. It is published here with permission from Herefordshire District Council Specialist Support Services, Children and Young People’s Directorate.

For the free guide please visit www.rnib.org.uk/insightmagazine



In the moment

In the Moment is a new DVD from Mencap. It looks at the work of 4 companies who work in the arts with people with profound and multiple learning disabilities.

They are:

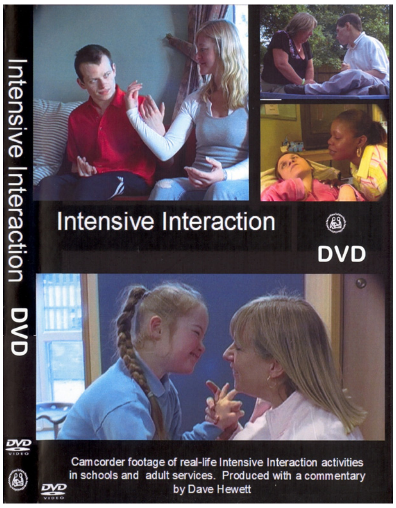
- Oily Cart do theatre work
- Project Art Works do visual art like painting
- Soundabout do music
- The Unlimited Company do storytelling.

In the Moment looks at why we should make the arts available to people with profound and multiple learning disabilities. We hope it will encourage more artists and organisations to become involved in this exciting area of work.

Purchase In the Moment DVD

You can purchase it from **Mencap's trading team** by calling **020 7696 6993** or trading@mencap.org.uk

Price: £15 (including postage and packaging)



Intensive Interaction DVD

A one-hour presentation containing scenes of Intensive Interaction activities. The activities have been shot in special schools and in residential and day services for adults

Disc content includes:

Eight scenes in different settings showing work with pupils and service users of all ages
Voice-over commentary by Dave Hewett outlining Intensive Interaction principals and learning outcomes
Interviews with practitioners and parents
Full menus for disc navigation

The DVD has been edited and produced by Dave Hewett, independent consultant, trainer and author who has worked on the development and dissemination of Intensive interaction for twenty years. The footage has been shot with camcorders in real-life situations and is of good and viewable, but not broadcast quality.

The disc price is £20 and can be obtained by contacting Sarah Forde by emailing sarahinteract@hotmail.com or telephone **01920 822027**

All profits will go to the Intensive Interaction Institute.

Free Symptom Control Manual

The 2007 edition of a children's palliative care symptom control manual has been launched and is now ready to download at the ACT website, ***free of charge***. The manual, *Basic Symptom Control in Paediatric Palliative Care: the Rainbows Children's Hospice Guidelines,* now in its seventh year, and used by doctors and nurses throughout the world, is the only resource which provides comprehensive guidelines for treating a wide range of symptoms experienced by children with life-limiting or complex health conditions.

As well as being an "industry bible" for professionals, the manual has also been prepared for the use of parents who are caring for a terminally ill child. Basic Symptom Control in Paediatric Palliative Care: the Rainbows Children's Hospice Guidelines, has been written by Dr Satbir Singh Jassal, GP and Medical Director at Rainbows Children's Hospice, and is a collaboration from 27 leading paediatric and palliative care contributors from around the world.

Individual Subscribers - To enhance our funds, we would be grateful if you agree to Gift Aid

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Details of donor:

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You must pay an amount of Income Tax and/or Capital Gains Tax at least equal to the tax that the charity reclaims on your donations in the appropriate tax year (i.e. 28p for each £1 you give up to 5 April 2008 & then 25p for each £1 you give on or after 6 April 2008)

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NOTES

1. You can cancel this Declaration at any time by notifying the charity
2. If in the future your circumstances change and you no longer pay tax on your income and capital gains equal to the tax that the charity reclaims, you can cancel your declaration
3. If you pay tax at the higher rate you can claim further tax relief in your Self Assessment tax return.
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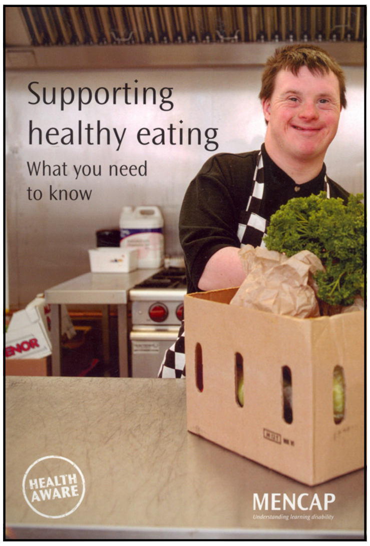
5. Please notify the charity if you change your name or address

Please return this form to PMLD-Link, 31 Birdwell Road, Long Ashton, Bristol, BS41 9BD

PUBLICATIONS



Publisher: Mencap

Product Code: HA001

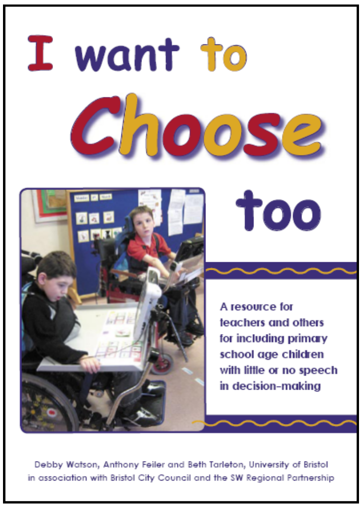
Pub Date: 2007

Price: £10

Supporting Healthy Eating

As part of the research into this resource, Mencap has discovered that many staff members felt they didn't have enough information themselves to help the people they support with their food choices. They felt that they needed to be equipped with nutrition knowledge themselves so that they could relay this information to the people they support on a day to day basis.

The aim of the pack is for this information to be readily available. It is a resource that should be used everyday and it is not a resource which should be left on a shelf to collect dust! The pack contains useful tables, tips and ideas and should be used at all meal times, shopping trips or meal planning.



Author(s): Debby Watson, Anthony Feiler and Beth Tarleton

Publisher: The University of Bristol

ISBN: 978-1-874291-33-6

Pub Date: 2007

Price: £N/A

I want to choose too

This is a resource for teachers and others for including primary school age children with little or no speech in decision-making. It was written by Debbie Watson, Anthony Feiler and Beth Tarleton from the University of Bristol in association with Bristol City Council and the SW SEN Regional Partnership. The project within which they developed the resource was funded by the Esmee Fairbairn Foundation.

Two schools were involved in the project, one for children with physical disabilities and the other for children with severe learning difficulties. 11 children with little or no speech contributed to the project, including children with PMLD.
For a copy:

http://www.sw-special.co.uk/parents/students/docs/iwanttochoosetoo.pdf

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Author(s): edited by Peter Limbrick

Publisher: Interconnections

ISBN: 0-9540976-3-7

Pub Date: 2007

Price: £17.50

Family-Centred Support for Children with Disabilities and Special Needs

This is a collection of essays that promote awareness and understanding of families in the people who manage and work in the services that attempt to support them and describe approaches that are designed for a family-centred standpoint.

The text can be used as a training and professional development resource to help everyone look beyond the child to the family, to understand that the family has strengths and needs just as the child does, and to respect and nurture the family as the child's first and persisting support system.

Managing Continence

Three books are designed to help all those concerned with managing continence.

bild

Managing continence

Everybody needs toilets

an easy guide for people with a learning disability

Alice Bradley, Mary Buchanan, John Dawson and Agnes Forsyth

Everybody Needs Toilets: an easy guide for people with a learning disability
Alice Bradley, Mary Buchanan, John Dawson and Agnes Forsyth

2006 ISBN 1 904082 83 1 Price £8.00

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

Relatively little has been written about continence in relation to people with a learning disability. Everybody Needs Toilets has been produced in partnership with people who have a learning disability to rectify this situation. The issues covered are those which the people involved felt were most pertinent to their needs and those of others. They should provide stimulus for discussion.

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

bild

Managing continence

Helping people with learning disabilities manage continence

a workbook for support workers and carers

Alice Bradley with Loretto Lambe

Helping people with learning disabilities manage continence: a workbook for support workers and carers
Alice Bradley with Loretto Lambe

2006 ISBN 1 904082 82 3 Price £12.00

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

By understanding continence better and improving the support available, care staff can help enhance the quality of life for individuals and, where relevant, for their families.

bild

Managing continence

Supporting continence management

a reader for managers

Alice Bradley with Loretto Lambe

Supporting continence management: a reader for managers
Alice Bradley with Loretto Lambe

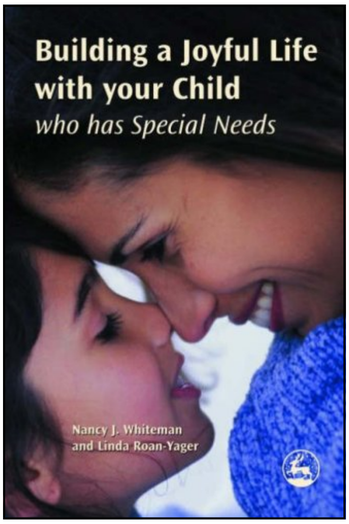
2006 ISBN 1 904082 84 X Price £20.00

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

REVIEWS

Title: Building a Joyful Life with your Child who has Special Needs.

Authors: Nancy J. Whiteman and Linda Roan – Yager



Pub date: 2006

ISBN: 9781843108412 .

As I started to read the book I realised what a valuable tool this could be for Parents/Carers but also for professionals to access and understand the stages of transformation a family will have to go through and the length of time experienced, before acceptance can take place. All too often, professional people give the impression that reading information from a book is enough to gain understanding, but families know that no one knows better than those who live with the issues around 'Special Needs', day in day out.

For parents, this book helps guide you through all the stages of coming to terms with a child that is different from other children. Having a child with 'Special Needs' can be very demanding and at times traumatic. Using a series of self help activities and family experiences, the authors help you face up to various feelings and emotions and by doing so help you become a better person and consequently a better 'Carer'.

Through the 'Person Centred' activities you learn to accept it's okay to feel conflicting emotions at the same time and experience a '<u>Twisted Skein</u>' (as described in the book) of emotions and that all parents take this journey until they reach a stage where they can accept and move forward.

By using a 'Person Centred' approach, the authors are not only up to date with their thinking but help the parent put themselves at the centre and by doing so can enable the parent to value their self-worth and needs as an individual. Working on these areas help a person to focus on what is needed to improve certain situations to improve 'quality of life', which in turn will benefit all involved.

Although I feel I am an experienced parent, having raised my two sons who have 'Autism' and the complex needs that come with the condition, I could relate to all the levels of emotion that were detailed.

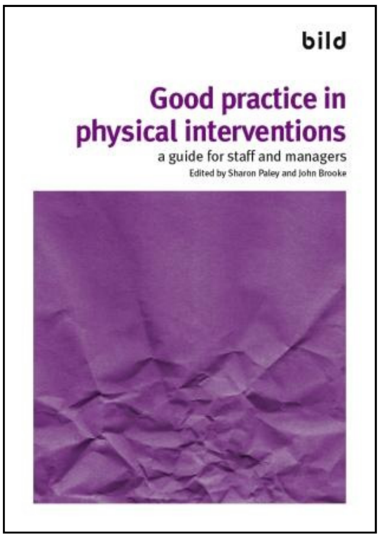
I found the book very enjoyable and would have relished it at the beginning of my particular journey.

Costing approx £12, I feel it is excellent value and would highly recommend it to individuals and professionals. I think support groups and Carer groups would also be a good idea, especially for less able parents who may find it more helpful to have other families to experience the activities with, rather than do them alone.

Dawn Rooke - Parent

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

Authors: edited by Sharon Paley and John Brooke



Publisher: British Institute of Learning Disabilities

ISBN: Pbk – 1-904082-74-2
Pub Date: 2006

Price: £20

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

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

Rob Ashdown, Head Teacher, St.Lukes Primary School, Scunthorpe

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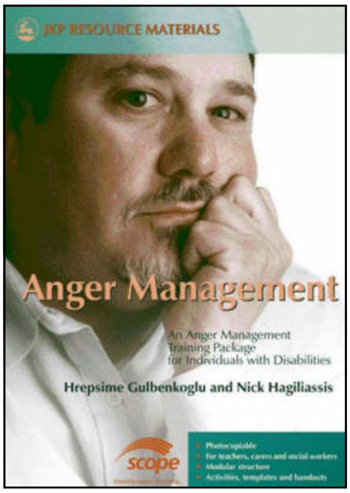
Title: Anger Management: An anger management package for individuals with disabilities

Authors: Gulbenkoglu, H. & Hagiliassis, N.

Pub date: 2006

ISBN: 1843104369



This publication is presented as "…a complete training package for helping people with intellectual or physical disabilities to manage feelings of anger in a constructive and effective way." No mention is made specifically of people with profound and multiple learning difficulties, but I think it unlikely that such learning needs could be met through this package, unless significant adjustment was made to the content.

It consists of 12 group sessions, with a fairly prescriptive script and structure, intended to take a group from "getting to know you", through "Learning about Feelings and Anger" and onto techniques for "Relaxing", "Thinking Calmly" and "Handling Problems" and "Speaking up for Ourselves". Each session is intended to last about 2 hours and follows a very similar format, with some simply expressed learning aims, resource material in the form of handouts with accompanying words and drawings, and a brief outline of the session plan. The format followed would be familiar to anyone who has attended or facilitated an anger management course and sticks very much to the tried and tested content of such events.

The difficulty with all "off the shelf" courses like this, is that the preciseness of the structure and the prescriptive nature of the script and content can, if followed too religiously, act as a restraint on the attendees of such courses and not allow them to make their own personal sense of the material. Clearly this package would need an experienced facilitator who could then tailor it to the group concerned. If this is the case, the facilitator would surely wish, in full negotiation with the participants, to design their own material and their own sessions so that it was a much more personalised approach to the subject. The market for this package is therefore, to my mind, difficult to determine.

Whilst this explores appropriate content and a reasonably clear structure, the use of pictograms for the resources are rather dated in style and again seem to militate against the personalized approach to such training which is surely at the heart of all such courses which aim to enhance the individual skills and raise the self awareness of the participants. If this is intended for the experienced course designer then I am not sure they will need it so prescriptively presented: if it is intended for those new to such facilitation, then such prescription will make the creation of a personalised approach to the learning difficult to attain. It seems to fall between these two "stools" and therefore fails on both accounts.

Robert PARDOE
Senior Lecturer, BSc, RNLD, DipSW, PGCE,
Faculty of Health and Life Sciences,
UWE Bristol.

Short Courses and 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

Catalyst Education Resources Ltd

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

Concept Training

15 Beach Street,
Morecambe,
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

Sunfield PDC

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

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

January

Date: 20th
Title: Widget Symbols for communication Incorporating Writing with Symbols & Communicate in Print 2
Provider: Sunfield PDC
Contact: (See Providers Details)

Date: 25th
Title: Communication and Supporting Skills Workshops for Parents of Children and Adults with Disabilities
Provider: NIID National Institute for Intellectual Disability, Dublin
Contact: Executive Officer: Ailish Kennedy
Phone: 01 896 3885 Fax: 01 677 9131
akenned@tcd.ie

Date: 27th
Title: Restrictive physical interventions practice issues
Provider: BILD
Contact: (See Providers Details)

Date: Various workshop dates
Title: Understanding the Multi-Sensory Concept
Provider: Concept Training
Contact: (See Providers Details)

February

Date: 1st
Title: Sex and the 3Rs—Rights, Relationships & Responsibilites
Provider: Sunfield PDC
Contact: (See Providers Details)

Date: 4th
Title: Developing early communication and literacy skills. High and low tech approaches in and out of the sensory studio
Provider: Hirstwood Training Ltd
Contact:
Telephone 01524 42 63 95
Fax 01524 45 20 54
email richardhirstwood@gmail.com
website www.hirstwood.com

Date: 5th
Title: Visual, Hearing & Speech Impairments
Provider: Sunfield PDC
Contact: (See Providers Details)

February

Date: 7th
Title: An Intorduction to Makaton
Provider: Sunfield PDC
Contact: (See Providers Details)

Date: 8th
Title: The emotional impact of self injurious behaviour
Provider: BILD
Contact: (See Providers Details)

Date: 8th
Title: Do you see what imean
Provider: RNIB
Contact: Angela Cardoso
RNIB London and South East
105 Judd Street
London
WC1H 9NE
Telephone: 020 7391 2245
Fax: 020 7391 2195
Email: RNIBLondonandSouthEast@rnib.org.uk

Date: 19th
Title: Completing the DLA form for children with an Autistic Spectrum Disorder
Provider: Sunfield PDC
Contact: (See Providers Details)

Date: 20th
Title: Understanding & Managing Sensory related behaviour
Provider: Sunfield PDC
Contact: (See Providers Details)

Date: 21st
Title: Intensive Interaction
Provider: Sunfield PDC
Contact: (See Providers Details)

Date: 1st, 8th, 15th, 22nd
Title: Communication and Supporting Skills Workshops for Parents of Children and Adults with Disabilities
Provider: NIID National Institute for Intellectual Disability
Contact: Executive Officer: Ailish Kennedy
Phone: 01 896 3885 Fax: 01 677 9131
akenned@tcd.ie

Date: 26th
Title: Children and young people with learning disabilities and complex health needs
Provider: Inclusion Distribution
Contact: Tel: 01625 269243
Fax: 01625 269243
Email: kevin.reeves@jan-net.co.uk
FREE EVENT (Voluntary financial contribution invited)

March

Date: 4th
Title: Exploring the benefits & impact of specialist status for special schools
Provider: Sunfield PDC
Contact: (See Providers Details)

April

Date: 5th
Title: The use of mechanical devices in the physical restraint of people who have learning disabilities
Provider: BILD
Contact: (See Providers Details)

Date: Various workshop dates
Title: Sensory Play and Leisure in the Multi-Sensory Environment
Provider: Concept Training
Contact: (See Providers Details)

Date: Various workshop dates
Title: **Sensory Differences and the Role of Positive Touch**
Provider: Concept Training
Contact: (See Providers Details)

Date: Various workshop dates
Title: Successful Multi-Sensory Sessions
Provider: Concept Training
Contact: (See Providers Details)

June

Date: 20th
Title: Sherborne Developmental Movement (Level One)
Provider: EQUALS
Location: Birmingham
Contact: (See Provider Details)

September

Date: 12th, 13th
Title: Quality Communication: for Pupil who are Deafblind (MSI)
Provider: University of Northampton (Subsidised costs)
Contact: Patsy Hollingum: Tel No 01604 893447
education@northampton.ac.uk

LONGER COURSES (with accreditation)

Updated June 2007

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

MA in Education
SLD2: Pupils with Severe and Profound and Multiple Learning Difficulties (Curriculum & Teaching)
This module addresses the requirements of the Teacher Development Agency (TDA) National Special Educational Needs Standards (Core 1a – 1e, Extension 2.i – 2iv.). It is directly related to the module Curriculum and Teaching – Pupils with Severe and Profound and Multiple Learning Difficulties which addresses further standards. The module provides students with an opportunity to gain an understanding of those influences which impact upon the learning, development and management of pupils with severe and profound and multiple learning difficulties. **Module: EDUM055**
For further Details: The University of Northampton. Tel: 01604 892192. E-mail: admissions@northampton.ac.uk

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

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

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

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

BSc in Professional Practice (Learning Disability Pathway)

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

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

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

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

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

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

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

Students working on BPhil or Postgraduate Diploma programmes with some additional activities can, on successful completion, be recognised as meeting the requirements of the DfES for the mandatory qualification for teachers of children with multisensory impairments.
For further details: University of Birmingham Dr Liz Hodges on 0121-414 4873 or email: e.m.hodges@bham.ac.uk

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

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

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

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

Postgraduate Certificate/Diploma Profound Learning Disability and Multi-Sensory Impairment Programme
MSc Learning Disability and Multi-Sensory Impairment Programme
Programmes available by Distance Learning at The University of Manchester, School of Education
Programme Aims

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

Programme Structure
Courses are delivered by Distance Learning over a period of 1 - 3 years (including an extra year of independent study for MSc. students undertaking their dissertation). The MSc and Postgraduate Diploma are also available full time (distance learning) over 1 year. The written materials are underpinned by a variety of Study School formats during this time. Student support is also provided by telephone contact with the academic tutors. There are no examinations and the course requires approximately 3-4 hours private study per week.
For further details: University of Manchester Janet Grimshaw, Phone: 0161 275 3463, Email: janet.grimshaw@manchester.ac.uk

MSc in Advanced Practice (Learning Disabilities)

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

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

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

The next intake is October 2006.
The programme leads to further qualifications at Diploma and Masters level.
For further details: University of St. Andrews http://psy.st-andrews.ac.uk/people/personal/mc1/
Dr Martin Campbell email: mc1@st-andrews.ac.uk

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

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