**SUMMER 1997** 

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# PMLD & LINK

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

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EDITORIAL Summer 1997

What a wealth of ideas and information this topic has produced! Museums, gardens cycling, adapted games, outdoor adventure courses - the ideas are so exciting that I am sure many of you will be dying to take up some of them to use in your own work, or they will stimulate your own ideas to develop. Luckily not all of them are necessarily outdoor activities, and so you don't need to wait until next summer, they can be developed during the months when we have to stay inside most of the time.

A number of our contributors are from Scotland and it is certainly a good place to be if outdoor activities are what you are look interested in.

Of course, we also have articles with a different focus - a textile project in Dundee, exploring literature, and the text of a keynote lecture at a conference in Luxembourg on Communication for All.

Many thanks to all the people who sent us articles. What enthusiasm they show, and dedicated thinking and planning to make life better for people with PMLD. They really help to keep ideas and information flowing - something that is not always easy in such a small field.

Do keep writing - about anything at all that you would like to share with others, and don't forget that you can ask for help as well as writing articles telling us about your work. Let us know if you have found a particularly useful piece of equipment - or book or article. You may think that everyone knows about it, but not everyone will, and they may find it just the thing they were looking for or, conversely, something they had never thought of, but will now try. Tell us about the things that haven't worked as well - someone might have a good tip that could make matters better.

The topic for our next issue is how we assess quality in our own provision. What criteria do we use to do this? Joan Boucher starts the discussion in Future Focus but please write in with your ideas about this.

#### **BUSINESS MATTERS**

**Subscriptions:** This is the last issue of this subscription year. Subscriptions should be renewed in September for 1997/98. If you do not renew your subscription you will still receive a copy of the Winter issue (another chance to renew) but after that, they will stop coming! Many thanks to all of you who have already renewed - it is good to know that you value your PMLD-Link.

#### Articles:

Material to be included in the next issue should reach me by the first week in November. Please can you send articles with good margins in single line spacing printed on one side of the paper only. I look forward from hearing from you with your contributions!

Carol Ouvry

PMLD-Link, The Old Rectory, Hope Mansell, Ross-on-Wye, Herefords HR9 5TL

# A RELIGIOUS SENSORY GARDEN AT DAME EVELYN FOX SCHOOL

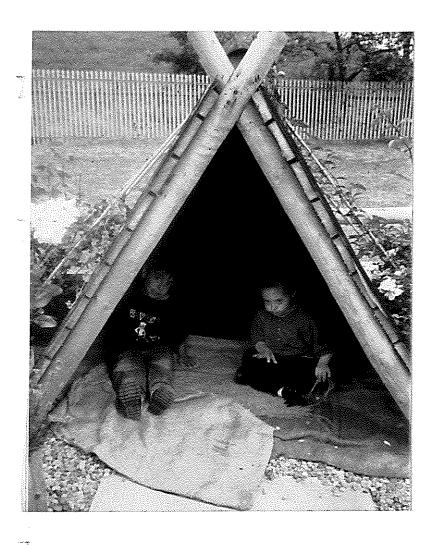
On 18th July 1997 local representatives from the Christian, Islam and Hindu faiths gathered to open the religious sensory garden which has been created at Dame Evelyn Fox school.

The garden was planned and designed by Alexandra Walker, the school's religious education co-ordinator. She has overall responsibility for the development of the garden. The practical aspects of creating the garden have been organised by Ann Coates, assisted by the students of the Bridge Unit (16 to 19 year olds). The students, under the guidance of Ann Coates, will be responsible for the garden's general care and upkeep.

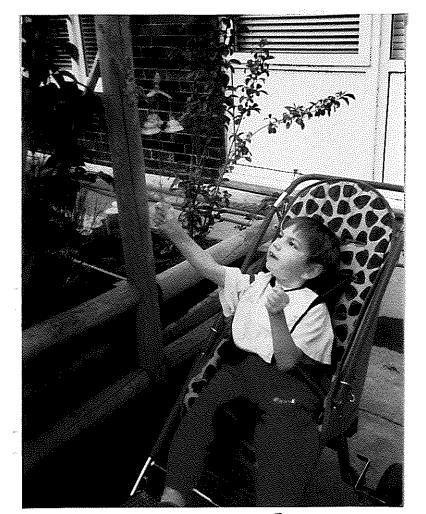
The photographs were taken at the opening ceremony, and the description of the project was handed out to people who attended the ceremony.



Mrs. Walker with students from the Bridge Unit who helped to create our garden



Two pupils in the Islam area inside the structure symbolic of Muhammed's cave



A pupil ringing the bell at the entrance archway to announce his arrival



# DAME EVELYN FOX SCHOOL

# **RELIGIOUS SENSORY GARDEN**

In April, 1996, Dame Evelyn Fox School was amongst eleven schools in the country to be granted one of 'The National Association of SACRES and St. Peter's Saltley Trust Religious Education of Collective Worship Awards'. The project aim was to create an outdoor area for the use of all pupils in the school, but specifically designed to provide a multi-sensory garden to support the development and understanding of Religious Education for pupils with profound and multiple learning difficulties (PMLD), enhance their learning experiences and increase awareness of world religions through a practical, experimental approach.

## **Religious Education**

The provision of a sensory garden which has particular features associated with specific religions, will create a stimulating environment in which pupils with PMLD can learn awareness of others and their needs, and awareness of the world around them. It will create an atmosphere designed the encourage the development of a sense of awe and wonder, and awareness of religious feeling; give opportunities for pupils to be assisted in exploration of similarities and differences in major world religions (emphasis being placed on Christianity, Islam and Hinduism, which are the three progressed religions chosen according to the school population); create a special environment in which to celebrate festivals of major world religions, and a place of stillness, privacy, belonging and reflection, both alone and with parents, friends, religious leaders etc.

Through these experiences, pupils will be guided in their exploration of how people relate to each other and begin to form some concept of community as outlined by Section 1:5 of the Lancashire Agreed Syllabus.

#### Collective Worship

Collective Worship at Dame Evelyn Fox School, is intended as a time of quiet reflection - an opportunity to peacefully gather thoughts together at an appropriate moment in a busy school day. The provision of a special place (in addition to quiet areas in the classroom), which is easily recognised with the aid of tactile, sound, smell, auditory and taste clues, will enhance the experiences of all pupils, by encouraging awareness of surroundings, atmosphere, and development of the numinous sense. The flexible timing of Collective Worship will allow each class to have frequent access to

the religious sensory garden, which is large enough for two or three classes to gather together for special occasions.

#### The Garden

The entrance to the area will be through a wide archway over which trailing plants will be trained. Bells will be attached to the archway at wheelchair height, so that pupils may have an auditory clue to announce their arrival to themselves and others. A central area will provide access to the three separate areas dedicated to Christianity, Islam and Hinduism. In this central area, will be a sundial, a bird bath and a bird table (passing of time and caring for living creatures is integral to all of the major world religions).

At the entrance to each area, a carved symbol appropriate to the particular religion will provide a tactile/visual clue, as will the three different floor surfaces. Each area will have a display table (made by students in the Bridge Unit), and many tubs containing herbs, plants, flowers, trees, fruit bushes etc., some chosen for their significance to the different religions, others chosen for their aroma, taste, appearance, texture and the sounds they make. In addition each area will have a special artefact particularly significant to that religion:

**Islam** - a covered wooden structure, symbolic of Muhammed's Cave, will provide opportunities for experiencing a dark, sheltered, quiet and safe place.

**Christianity** - a rockery, with a large cross (designed and decorated by students in the Bridge Unit) - tactile and visual clues to the symbols of Christianity.

**Hinduism**- a Mandir Shrine and incense on a stone pedestal - symbolic of prayer ritual and providing visual and aromatic clues.

#### An on-going project

Our religious sensory garden has been designed to create a special place where all pupils will be able to experience Religious Education and Collective Worship in an atmosphere encouraging curiosity and developing awareness of others and their needs, beliefs and cultures. Although specifically designed with multi-sensory clues to allow PMLD pupils to explore the world around them, the benefits of creating a special atmosphere in such environment will extend to all pupils within the school, and encourage additional opportunities for links and mainstream peers, religious leaders and the community as a whole. All pupils will be given opportunities to take responsibility for caring for our garden as it develops throughout the years to come.

#### Alexandra Walker

RE Co-ordinator, Dame Evelyn Fox School, Roman Road, Blacburn, BB1 2LA Telephone 01254 568808



# WHY DON'T WE GO TO THE MUSEUM?

Visiting museums, galleries and historic sites may not seem the most obvious leisure activities for people with PMLD. However, INTACT, the Intellectual Access Trust, is hoping to change that by working to improve access to information about the objects and works of art on display, or even the site itself, for people with a wide range of learning and communication disabilities so that they can have a more enjoyable and interesting experience.

INTACT was set up by a group concerned with improving access for people with learning disabilities who were inspired by the idea of making the new Museum of Scotland, currently being built in Edinburgh, truly accessible to all. After the necessary funding was raised (no mean feat), I was appointed as Project Officer in May 1996 on a two year contract. My remit is:

- \* to research what work had been done in this area;
- \* consult with people with learning disabilities along with their parents, teachers and carers and with staff in museums and galleries to look at what could be done to improve intellectual access;
- \* try out some of these ideas in a number of pilot projects in order to evaluate their success:
- \* and finally write up the results in a report which would be circulated to museums and galleries throughout Britain and run a number of training sessions, based on these findings, to encourage them to apply some of the ideas in their own institutions.

INTACT is committed to improving access across the whole range of learning disabilities and hopes that improvements in this area will also help many of the general public who are not confident readers. However I have a particular interest in helping adults and children with PMLD as I have had some experience in working with this group and recognise their need for increased choice and opportunities to develop interests, preferably within the ordinary provision in the community. The benefits in terms of social, aesthetic, sensory and emotional growth are immense.

Most visitors to museums and galleries, as well as to historic sites and buildings, heritage centres, country parks and even zoos, now expect more than just to look at objects, pictures or animals. They want information about the what, how and why in an accessible form. This means that relying solely on written information is no longer acceptable.

Providing accessible information involves using alternative means of presenting it, such as

- greater use of clear pictures and diagrams
- showing an object in a context such as a diorama or room setting
- \* audio
- \* video
- \* interactive displays (which can be anything from lo-tech panels to lift up to discover the answer to a question to user-friendly computers)
- \* opportunities to touch, feel and eyen, where appropriate, to taste and smell.

Such developments are good news for people with any kind of sensory or learning disability and, as they become more widespread, will make museums and galleries more inclusive and accessible to all. Where people with PMLD are able to access information about museums objects, through whatever medium, this widens their experience and gives greater opportunities for choice.

One of the aims of INTACT is to raise awareness among museum staff to the needs of people with learning disabilities and to encourage them to work together to find ways of overcoming problems. We are consulting with PAMIS, based in Dundee, to look at ways in which we can improve access for their service users, children and adults with profound and multiple impairments, and to build links with the local museum service.

We are hopeful that one result of this collaboration will be that the new Arts Centre in Dundee, now being built, will be fully accessible in every sense. It will include multi-sensory exhibitions which will be of interest to people with PMLD as well as the general public (an example is "Changing Perceptions" which was in the City Art Centre, Edinburgh earlier this year and had light projections, tactile and sound sculptures, and a scent installation). There will also be opportunities for people with PMLD to exhibit their own art work in a prestigious venue.

Museums and galleries are already trying to reach out to new audiences, and many have gone a long way towards improving physical access for those with mobility problems, and in considering the needs of those with visual or hearing impairments, though there is still some way to go. These trends, along with the Disability Discrimination Act of 1996, mean that museums and galleries are more aware of the need to cater for those with disabilities and are more receptive to suggestions.

Signed tours for those with hearing impairment or touch tours and tactile aids for people with a vision impairment are now not uncommon, and this has come about because there was a demand for these services. Similarly, if there is a demand for a service for people with PMLD, most museums will be sympathetic although they may need advice on how to go about this. Often all that is needed is a little imagination and a willingness to recognise that everyone has a right to enjoy the objects and works of art of the collection.

Many museums already have objects which can be handled, though not on open display, and would be willing to arrange a "hands-on" session if approached. INTACT has been able to extend the handling training sessions at the Royal Museum in Edinburgh, originally for school-teachers, to staff from adult day centres and from college special needs departments. This means that they are then able to bring groups of students to the museum to use the handling collections which vary from Victorian clothing and domestic items to Rocks and Minerals, which includes fossil-casting.

Contemporary art exhibitions often have displays in a variety of media, such as light, video or tactile art which are accessible to disabled and non-disabled

people alike. Many organise workshops in association with their exhibitions for a variety of community groups.

At a site in the Scottish Borders, INTACT has been working with Historic Scotland to look at ways of promoting some of the facilities there, such as carved stones which can be touched, the herb garden which has wonderful smells in summer and the friendly welcoming staff who are eager to communicate their enthousiasm though the site, by its nature, has only very limited access for those who use wheelchairs.

We feel that the INTACT Project has already had some success in raising awareness of the problems of those with PMLD and other learning disabilities among museum staff. We are trying to encourage partnerships between them and people with disabilities and those who care for them, so that they can work together to make museums and galleries more attractive, interesting and stimulating places to visit. If parents and carers of those with PMLD voice their needs, we would hope that they would get a sympathetic response.

INTACT would welcome welcome readers' comments about their experiences of visits to museums, galleries or historic buildings.

Ann Rayner, INTACT Project Officer, The Royal Museum, Chambers Street, Edinburgh, EH1 1JF

# 

You may have read a recent article on Tina Deteridge's work using IT with pupils who have profound and multiple learning difficulties. The study from which it came confirmed the importance of helping a pupil to develop a clear understanding of switches (cause) and how they interact with the device (effect). Following that paper Tina has drawn up a draft checklist to help practitioners to observe a person's response to a computer screen or other switch operated device. Because of all the different things going on at any time, it is often difficult for practitioners to observe as closely as they would like. This list, which is not definitive, is intended to help practitioners by giving suggestions of what to look for, and to have a means of recording.

Copies of the checklist are available for £3.00 - stamps or cheque to Tina Detheridge, 102 Radford Road, Leamington Spa, CV31 1LF or can be printed from the web free, from http://www.widgit.com/ - look under special neds/PMLD

# **MELDRETH GAMES - AN INTRODUCTION**

A challenge in attempting to introduce people to aspects of Meldreth Games in a short article like this is that many have very little knowledge of what they are, how they are played or even what they look like. If you are not among that number, all well and good, but if so, there is a problem that this article, I'm afraid, can only do a little to remedy.

What can be done, however, is to give a very brief insight into what is involved, and if your appetite is whetted, then there is an excellent 30 minute video available about the Games that can be rented or bought for a pittance that will open the world of Meldreth Games to your full view in a way that I cannot hope to achieve here.

A few years ago I was invited to Denmark to demonstrate the Games and had to supply a brief description of each game to circulate among those people who might be interested in attending the course. In a salesman-like mood I felt it might be advantageous to supply something a little upbeat, so I typed the following as an introduction to the individual games. I thought you might be interested in it too.

Meldreth Bowls - a skilful and fascinating carpet-bowling game. The aim: to home in as many bowls as possible into scoring positions on a coloured, circular target on the carpet and knock your opponent's bowls off. Ramp access devices and a unique scoreboard give physical and intellectual access to those who need them.

**Roboule** - a fast, exciting carpet-bowling game played toward a standing target with scoring 'arches'. The aim: to roll or knock bowls into the arches and 'rob' your opponent's bowls for the highest score. A two-tier rule system tests the abilities of all levels of players, however disabled.

Side Tennis a hard hitting, table return-ball game - lightening fast when played by the physically able, but with unique facilitating features to 'hold' and 'move' the ball that make it suitable for very disabled players.

Meldreth Billiards a skilful, strategically challenging form of billiards with a range of interesting access devices to make play possible for all levels of ability.

**Meldreth Cricket** - a fast batting and fielding game for the non-ambulant and those with limited physical skills. Can also be played by the more able. A pitch laid out with wickets, target nets and helpful access devices for those who need them makes a fast, exciting game for all ability levels.

Good prose (perhaps) but it may be that you are little the wiser after reading these descriptions than you were before you started. A way to enlighten the situation, perhaps, is to home in in detail on one of the games. A one f the first of the Meldreth series, Meldreth Bowls serves this purpose very well, also it highlights some key issues of sport and people with PMLD that are frequently passed over. It is unfortunate that they are, as there are rather essential concepts in this area which need to be addressed in order to make any sense of the situation at all.

A game that many are familiar with or have perhaps seen wile strolling through one of our more sedate public parks is the game of flat green bowls. In the singles version of this game a small white ball, a 'jack', is rolled 30 or 40 metres away from two people, each with 4 larger owls of a brown or black colour. The object for the bowlers is to try to

roll their bowls nearer to the jack than the other follows. If a bowler gets on of is bowls nearest he gets 1 point, 2 nearer 2 points, and so on. (Boccia, a game with smaller, softer bowls is an ancestor of lawn bowls. I mention it because it is played today by many disabled people). Among other problems for a large number of people with PMLD is the concept of 'near'. Many have severe difficulties with this concept per so, others are unable to recognise which bowl is nearest with so many lying in close proximity to the jack at different points of the compass to it. Yet others are unable to count. 1 nearer, 2 nearer, 3 or 4 - what does it all mean?

Meldreth Bowls is a game played on a bowling carpet that endeavours to solve some of these problems and a few more besides. In this game the target is not a jack but a horizontal circular target laid flush or dyed onto the surface of the carpet. It consists of a small inner blue circle surrounded by a middle green and an outer yellow ring (diameter of the whole target is about 1.5 metres). Two competitors roll 4 bowls each at the target from a carpeted ramp (for the most physically disabled) or a bowling mat. A bowl that lands in the blue central circle scores 4 points, while the green and yellow score 2 points and 1 respectively. The difficulties in understanding the concept of 'near' or of making fine visual judgements around a jack now simply do not arise. The problem of innumeracy is similarly removed by the use of a colour/size coded 'slot-in' type scoreboard. If a bowler scores a blue he is awarded a large blue scoring piece to slot into his scoreboard, if a green then a green piece half the size of the blue, and a yellow gains a yellow piece one quarter the size of the blue. The player with the biggest stack at the end of the game is the winner. No ability to count is required and bowlers can at the same time see exactly what colours they have scored during the game.

The wide carpeted ramp allows even very physically disabled players to participate 0-even a slight nudge of a bowl with one finger will start it moving from the flat delivery surface onto the bowling slope toward the target. (Narrow bowling 'gutters' are not usually used in Meldreth Games because they require alignment in a given direction by a helper. Many people with PMLD are, for a variety of reasons unable to specify the exact alignment of such a gutter. The wide ramp leaves the running of the important aspects of the game entirely in the hands of the player, addressing the all-important aspect of independence in making a play. How a player directs the bowl is the way it will go, not in a direction predetermined by a non-disabled assistant.

These and similar principles are the kind of things addressed by Meldreth series games. Experience would strongly suggest that they are essential to the successful running of games where PMLD is concerned.

Roboule is another bowling game using the same bowls, a carpet and identical ramp for the severely physically disabled as used in Meldreth Bowls. The target is somewhat different however - a standing wooden target, know as a 'bridge', 134 cm wide and 46 cm high with 3 large arches cut into its face, each marked by a colour as before - blue (scoring 4 points), green (2 points) and yellow (1 point. Players have 5 bowls each and the object of the game is to roll your bowls into the arches or knock your opponent's in to get the highest score. The name 'Rob-boule' reflects the fact that one ma augment one's own score by robbing an opponent's bowl, i.e. knocking it into an arch. The size/colour coded scoreboard is in operation in the same way as in Meldreth Bows and the game is in many ways more conceptually straightforward than its sister game.

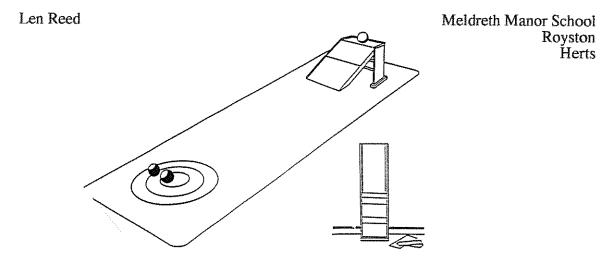
Seeing some of these games played by people with PMLDS is a real eye opener. Where there is an interest in ball games and access has previously been very limited or denied (at least at an *independent level* in any real sense of that concept) the enjoyment level is usually high. Once a player has homed in on the particular Meldreth Game he or she can play the best - something governed by physical and intellectual factors - some of the performances, even by very disabled participants, have to be seen to be fully appreciated. At this point I think it only fair to point out that there are many people with PMLD who haven't the slightest interest in such activities. Their interests lie elsewhere, in music or

art or whatever - a point true, of course, of the population in general but for the rest, Meldreth games provide an exciting alternative that (in the opinion of a totally non-biased mind!) ought always to be on the list of options for sporting involvement and activity.

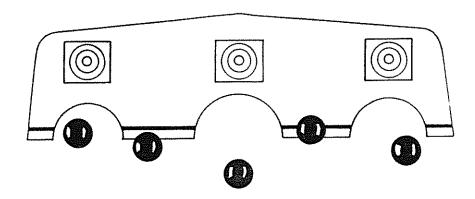
All of the Meldreth series games use the simplified scoring system described earlier. Each address the problem of intellectual and physical access fully. In addition they all have advanced rule systems that allow intellectually and physically able people to play at a competitive and challenging level. In other words, they should be a much fun for you or I to play as the most severely disabled competitor.

A plus for the summer is that both Meldreth Bowls and Roboule can be played outside. The carpets can be placed on a lawn as long as the surface if flat and more or less smooth. (You never really find out how bumpy your lawn is until you try to find a smooth, level place on it!). Side Tennis and Meldreth Billiards - games not discussed here but equally as interesting as the bowling games - can also be take outside with the same stipulation of a flat surface. Meldreth Cricket is exclusively an indoor game.

For anyone whose curiosity has been aroused and wants to know more about the games there are full rule books on each game (£1.50 each + postage and packing) and the video I mentioned earlier costs £0 +postage and packing. It is available from the author or Jenny Gore, Meldreth Manor School, Penny Lane, Meldreth, Herts. SGJ 6LG (telephone 01763 260771). The video can also be rented for a fortnight for £2.00+ postage and packing).



Meldreth Bowls equipment with 'slot-in' scoreboard



Roboule bridge

# PAMIS Parents and Professionals Special Interest Group (Tayside)

# Accessing Outdoor Activities

The PAMIS Parents and Professionals Special Interest Group (Tayside) has been in existence since August 1995. It is composed of parents and local professionals with a special interest in the needs of people with profound and multiple disability and of their carers. It aims to raise awareness of those needs in others, particularly decision-makers. Meetings occur regularly and offer an opportunity for families to raise practical concerns which can then be dealt with effectively by the Group as a whole. They are a useful forum for campaigning for rights and services, and also act as a means of exchanging information and obtaining advice.

#### Access Issues

Much of the Tayside Group's activities have been concerned with issues of access, particularly to leisure facilities and activities. The Group has taken two specific initiatives in this area:

- joint planning with Angus District Council Leisure and Recreation Department of a fully integrated play and leisure area at Forfar Lochside Country Park
- the provision of appropriate changing facilities for adults with disabilities at centres offering leisure activities and visitor attractions.

# Forfar Lochside Country Park Play and Leisure Area

This scheme, which has now been approved in principal by the Council for funding, is at the detailed planning stage. It was initiated by a parent member of the Group who lives in Angus, and is very much involved in the organisation of the Angus Summer Play Scheme. Having attended the PAMIS Workshop on Campaigning, she wrote to the Director of Leisure and Recreation for Angus, asking that consideration should be given to the needs of PMLD children in local playparks. She then followed up this initial contact by doing research amongst other parents of children with disabilities in Angus to establish the following information:

- the numbers of families currently excluded from using existing play provision in the area because of lack of suitably accessible equipment
- the distance families would be prepared to travel to use a good integrated play area

This information was passed on to Angus Council.

Angus is now planning to redevelop an existing play area, both for the use of local families and as an additional tourist attraction at a very pleasant Country Park. The PAMIS Group has worked with Council officers on layout, access, ramps, equipment, landscaping etc. and has identified potential users throughout Tayside. The aim is for a 'centre of excellence' which will provide an attractive and accessible leisure facility for all, regardless of age or degree of disability.

This project is unique because a fully integrated *public* play and leisure area is being designed *around the needs of children and young people with profound disabilities,* while being equally attractive to those without disabilities: the usual case is that the requirements of those with PMLD may well be only taken into consideration as a afterthought or 'add-on' to an existing design.

# Changing facilities for adults with disabilities

Many parents find that their daughter or son with disabilities is excluded from leisure pursuits because adequate changing facilities are not provided. In their absence, families often have to turn back during a day out, or else end up changing their daughter or son on a toilet floor - a very undignified and unhygienic procedure. The solution to this problem is to install a height-adjustable changing bench in the toilet provided for people with disabilities.

The PAMIS Group is negotiating with a number of agencies including the National Trust for Scotland, Forest Enterprise and Angus County Council about this issue. Collaboration with Dundee City Council has already resulted in the installation of changing benches at two of Dundee's public toilets, as well as at the Olympia Community Leisure Centre. Without appropriate changing facilities in 'toilets for the disabled', people with PMLD will be denied access to a number of ordinary activities, including leisure pursuits. PAMIS would like to encourage everyone working in the field of learning disabilities to actively campaign for this provision nationally, and has produced a Factsheet on this topic which is available to others. (To receive a copy, please send a SAE to the address below).

# Jessie Roberts, PAMIS Co-ordinator, Tayside

# pamis

PAMIS (Profound and Multiple Impairment Service) is a UK wide voluntary organisation, concerned with profound and multiple learning disability. Families caring for people with this degree of disability have a huge task and a right to as much support as can be offered. PAMIS aims to provide them with up-to-date information and practical help on all aspects of care, therapy, rights and entitlements.

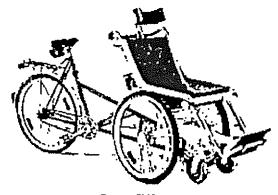
In association with ENABLE, PAMIS is currently running a programme of training workshops for parents and carers in the following areas of Scotland: Greater Glasgow, Angus, Dundee, Perth and Highland Region. The workshop topics are identified by parents themselves, and the course tutors are experts in the subject covered. The emphasis is always on **practical** help and advice. A more detailed account of the work of PAMIS will appear in a subsequent edition of PLMD Link.

For further information on PAMIS, please contact: PAMIS, White Top Research Unit, Frankland Building, The University, Dundee DD1 4HN Tel: 01382 345154

Registered Charity No. 1011895

# CYCLING FOR ALL - EXPLORING THE COUNTRYSIDE

At an ENABLE sponsored cycle at Strathclyde Country Park last year some PAMIS families were encouraged to take part by using the Duet adapted bike. This bike looks like a rickshaw. The wheelchair attachment at the front has a headrest, footplate, dense foam pads and a harness, all of which are adjustable to suit both adults and children. The wheelchair is easily detachable and can be used independently from the rest of the bike as a lightweight wheelchair so that everyone can enjoy a cafe stop on route.



Duet Bike

For the PAMIS families involved this has the first time that the whole family had been able to cycle together instead of the usual arrangement of one parent cycling with some of the children and the other parent and the person in the wheelchair left behind. The children with disabilities loved the experience of the speed and movement and wind in their faces and the siblings also thoroughly enjoyed the fun.

The parents decided that they wanted to be able to do this more often and so as a group, we set about two main issues which would make this possible, recognising that one would not work without the other.

- 1 Investigating the range of adapted bikes: We became aware very quickly that there were a number of adapted bikes to choose from.
- 2 Finding suitable places to cycle: We wanted good surfaces, traffic free zones, eg, cycle paths or country parks. Like our initial experience at Strathclyde Park, we wanted the bikes to be available for hire since their cost would inhibit purchase by individuals.

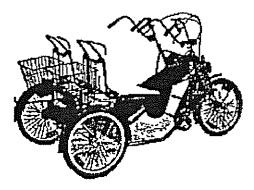
# **Adapted Bikes**

The range of bikes is very interesting and the families have tried various types both at demonstrations especially arranged for PAMIS by bicycle companies, and at country parks where such bikes are located outwith Glasgow.

We were very impressed by the first 'side-by-side' bike which we saw by chance at a visit to a Special Needs Adventure Playgroup in Edinburgh. This bike is simply like two ordinary bikes with one frame - rather like those seen in fairground roundabouts. The able bodied person has control of the steering and breaking. At first the parents loved the idea of their two children being able to cycle off into the sunset, but they felt the backrest and harness provided insufficient support for their particular children. However, having seen a side-by-side bike we chose to pursue this option and look at other designs.

The next side-by-side bike we saw was a Danish design (UK distributor, Pashley Cycles) which is much more suited to the PAMIS families' needs. It has two wheels at the back, one in front, has a low centre of gravity and an effective parking brake which makes getting on and off easy. It has two plastic 'cafe type' seats with cushion, headrest, harness and footplate and is therefore very comfortable and secure to sit in.

The able bodied person has control of the steering and brakes and can propel the bike alone if required. The person with disabilities has a set of handlebars and can pedal if they are able. If they are unable to do this, their feet can be strapped into adapted pedals which will go round as the other person cycles, thus providing useful exercise. However, if the person is unable to move their legs at all, or finds this too difficult, the pedals can be disengaged and the person's feet can then be securely strapped to a footplate. The handlebars on the person with disabilities' side can also be removed and replaced with a hand crank if people can manage this.



Side-by -Side Bike

# **Suitable Cycling Environment**

We initially approached SUSTRANS (an engineering charity which campaigns for and builds cycle paths nationally) who have been extremely helpful in identifying suitable places to cycle and in working with us to look at improving existing cycle paths within country parks.

We have also been working, with North Lanarkshire Social Work Department regarding Strathclyde Park, and East Renfrewshire Leisure and Recreation Department regarding Rouken Glen Park. The staff from both of these parks were very interested to meet local parents and hear their views. They joined the

PAMIS families at a few demonstrations of different types of bikes and the representatives from both parks were convinced enough to each buy a side-by-side bike for their own parks.

# Obtaining funding

We have now submitted an application to the Scottish Office Cycle Challenge Fund which was looking for innovative ways to encourage cycling. The application is to purchase and suitably locate a further 4 bikes. We were supported in the application by a number of other disability organisations. These are: Enable, Sense Scotland, Quarriers, and Capability (formerly the Scottish Council for Spastics).

We are very happy with progress so far, since, from an initial aim of investigating bikes and finding suitable places to cycle, we have managed to purchase two bikes and locate them in country parks. Additionally, if our grant application is successful a further four adapted bikes will be provided.

We are hoping that the bikes will be well used and be enjoyed by people with varying degrees of disability, but particularly those with profound and multiple learning disabilities. So far the siblings, friends and the PAMIS children have thoroughly enjoyed the new cycling experience and surely the fun involved is the best way to encourage integrated play and offer opportunities to explore the countryside.

We would be most interested to hear from other groups of similar initiatives or of other equipment that will enable people with profound disabilities to participate in leisure activities.

# **Lesley Houston**

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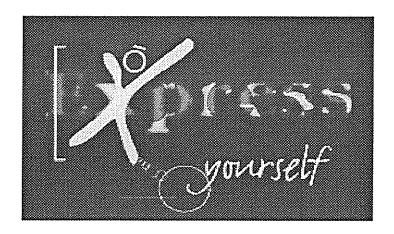
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The White Top Centre in Dundee provides a day service for adults with profound and multiple learning disabilities. As part of a wide-ranging curriculum, skills tutors working in the Centre have focused in particular on the use of the creative arts with this group, and how the arts can be used to improve access to the community. In the first half of this year two groups of service users have been involved in two community arts workshops. The first of these was a Textile Project in Dundee's Verdant Works, an interactive museum dedicated to Dundee's past as a centre for jute manufacture. The second was as part of the 'Express Yourself' exhibition. Together these initiatives culminated in an exhibition at the McManus Galleries, in Dundee's principal art gallery.

The projects provided a distinct opportunity for service users to become part of the creative machinery. In the Verdant Works Project, a group textile piece was produced, while the Express Yourself exhibition involved an installation. The ultimate aim of both projects was to experience and state, through the creative process and outcome, community presence and participation.

Verdant Works Textile Project involved six community groups from a very broad spectrum. The concept of the work was to represent Dundee's jute heritage from many vantage points. Consequently each group took a subsidiary theme which was later brought together with all the other work to make one large piece. This process almost inevitably lead to an abstract and multi-textural representation. It was difficult to see the final work as six separate pieces. Rather the six groups' work complemented each other thus binding them together as one.

The White Top Centre service users' input came in the form of tapestry and felt making, using net, silk, wool, cotton, leather, yarn, paper and plastic as materials. Both the felt-making and weaving were very interactive, in that the arts worker and myself enabled the three male participants to sense, feel and use the materials. The work required hand over hand intervention as all the men had a visual impairment and were sensitive to touch. We also used backward chaining methods in order that they were enabled to complete significant tasks, within the weaving process. The men's responses to the work process did appear to develop in that they held on longer to materials,

tolerated different movements, looked up at materials and equipment and that their general alertness increased. All these responses ultimately increased the output of work i.e. thirteen tapestries and twelve felt pieces were completed. These are on display at Verdant Works as part of their permanent exhibits.

The Express Yourself Workshops involved four service users, two women and two men. Three community arts workers, a Speech and Language Therapist and myself (an art therapist) worked on this project with the group. The idea came from staff at the centre who wanted to create a multi-sensory experience which would encourage individual service users to express themselves by actively promoting visual, tactile and auditory stimulation of the senses. Already inspired by the sensory environments created by Hulsegge's and Verheul's 'Snoezelen' and by Lilli Nielsen's work with visually impaired people, the installation took the form of a large and inviting darkened box. This was to reduce outside distractions, therefore increasing opportunities for attention, awareness, anticipation and participation.

The project allowed for opportunities to:

- extend hand-to-eye co-ordination
- · explore cause and effect, and
- · develop understanding and expression.

All ultimately leading to control of the environment.

There were several sessions of preparatory work exploring a variety of stimuli with participants, ascertaining what appeared to trigger different senses: sight, hearing, touch, movement, smell and taste. Background notes were taken and used to plan further sessions that would develop the interests of each person leading to the creation of an individual sensory object for that person. For instance, a convex mirror surrounded by ropes of light and screened by net covered with sequins was developed for one of the women. A jelly bean switch was used by her to activate the lights, the nets partially hiding the mirror and her reflection. She might thus be encouraged to brush the nets aside to see her reflection and explore cause and effect.

In summary, the installation held four pieces reflecting the interests of the four service users involved. All objects will by their nature require further development as service users interact more frequently with them. Our installation, as part of the Express Yourself art exhibition is open to the public for a five month period.

These two workshops were an inspiration to staff and were a very positive experience for service users with regard to their interaction with outside people and agencies such as the arts workers, other community groups and museum staff. The links to the wider community via a creative process cannot be underestimated in terms of their value in empowering people with profound disabilities, and offering opportunities to them for choice making. They also made the individuals' presence known through particular skills and

in the very public format of a formal exhibition. These artistic creations inform others of the White Top Centre service users' creative skills and also provided opportunities for them to learn with and through others. Ultimately they exercised their right to express themselves and to be included with others in local artistic endeavours.

Both these arts projects clearly demonstrate ways in which intellectual access for people with profound and multiple learning disabilities can be achieved. These two successful ventures will be described as part of the Intact programme which is reported on elsewhere in this Newsletter.

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#### OUTDOOR ADVENTURE IS FOR ALL

The challenge of something different, the thrill and excitement of a new activity.... Long gone are the days when such opportunities were reserved for active fit young people or athletes. There is now a movement taking place, as an ever increasing number of outdoor centres offer stimulating, exciting and challenging outdoor activities for people with a wide variety of special needs, right across the age range from 6 to 90!

Activities such as sailing, canoeing, rock climbing, abseiling, together with the opportunity to sleep under canvas, cook (and in some cases find) your own food bring new dimensions and interpretations to everyday living. Many of us take for granted the fact that we have a great deal of choice in our lives, when we sleep, what we eat, what we wear, who we see etc. Addressing these issues and providing access to suitable activities can be problematical with pressures such as time, lack of transport, and available staff resources. Parents too can sometimes be over anxious about their children and young adults, unaware that the opportunity for adventure exists for them too.

If you have always been told that "You couldn't possibly do this, it's far too dangerous, you might get hurt" or "Don't do that, you'll get yourself dirty" you can be forgiven for imagining that the chance of taking part in a group problem solving exercise and the opportunity for learning it presents is not for you. If your supporters never imagined that you could take part, they will not think how to give you that opportunity. If it has always been denied to you, you don't know it exists, and you or your supporters will not fight to have it.

Each of us is different, each of us is unique. We all have our own fears, our own difficulties to overcome. By no means the panacea for all ills, outdoor adventure can be the means by which these are aired, explored and finally conquered. An example could be a sail in a dinghy. There might be some in the boat (students and staff alike) who have never been sailing, some who have been sailing, but never in the open sea. Some might like the motion of the boat through the water, others would worry about being sea sick. Members of the group might enjoy the sound of the waves against the hull, several might be concerned about being so far from shore. For some it could be a sensory experience - the smell of the sea, the feel of the wind through the hair, the heat of the sun on the skin. The list is endless.

Just one activity can conjure up a whole different set of responses, likes and dislikes. Each person will take something from the experience. Skilled and qualified staff at outdoor centres will design a course to meet the requirements of individuals and groups and these activities will then be adapted to allow each and every person the opportunity to take part in the activity programme, at whatever level to suit their needs and range of abilities. Safety is paramount and no one is forced to take part in an activity or complete a section which might prove difficult or dangerous. Instead the task is always explained, rationalised and demonstrated so that the person concerned or the enablers in a supporting role can make an informed choice whether they continue or not. A problem can almost always be overcome, sometimes with the assistance of the group and/or with help from the instructing staff.

Why take part in adventurous outdoor activities? For those in society so often denied the opportunity there can be many benefits, for there is a capacity within all of us to rise to a challenge. There is the change from the everyday routine, the freedom of being out of doors, an opportunity for staff and parents to reassess the capabilities and potential of their children or young adults through the stimulus of adventure, excitement and fun.

Personal expectations and horizons can be broadened especially when an individual or group are given the opportunity to succeed when given a structured and sequential task to complete. It is not unusual for people to express the apparent wish of non-involvement or to show a lack of interest because so many of their previous experiences are based on disappointment and 'failure'. Skills learned on an outdoor adventure course have a place in everyday life (a fact now recognised by many corporations and businesses who use Personal Development courses to motivate and develop the potential of their management and staff) and can often form the basis for further work, following on from a positive experience. This in turn can lead to increased self confidence, self reliance, and a feeling of self worth.

The proof of the pudding is in the eating so it is said. If you have been thinking of taking part in such a course, or taking a group to a specialised outdoor centre why not get in touch and discuss your needs and requirements. Be prepared to be involved from day one, there are no spectators, only participants!

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# **EXPLORING LITERATURE**

The power of music, art and dance as channels of communication, and avenues of creative expression have long been recognised in the field of learning disability (see Segal 1990). Literature - stories, plays and poetry - is a branch of the arts which presents particular challenges in this area: because literature is the art of language, and language development (be it spoken, manual or graphic) is of course severely limited in people with profound and multiple learning difficulties.

Why would we want to use literature anyway? The argument advanced within the National Curriculum is that of "heritage culture", that certain texts, such as Shakespeare's Henry V and Wordsworth's Daffodils have become national and cultural icons, familiarity with which helps to contribute to a sense of who we are. A more critical, less nationalistic approach would suggest that works of literature reflect their social context, laying notions of cultural value and identity open to question. Nevertheless, the cultural heritage argument does, we think, have some value for people with learning difficulties who have been so marginalised n our society 0 with the proviso that our community is multi-cultural, and that every culture has a literature to be explored and shared.

A second argument is that literature is about other people, and offers us the chance to develop imagination and empathy, by presenting us with other worlds, other perspectives into which we can enter, finding connections with our own experience and enabling us to gain insights into the experience of others. I am reminded of the mother of a young woman with a learning disability, who spoke movingly of how her daughter had fallen in love with a teacher at the age of fifteen, becoming obsessed and withdrawn when she realised the impossibility of the relationship. Severely depressed, she was treated with a combination of behavioural methods and medication. What was never offered to her were the stories of how other girls who have suffered for love: Juliet, Anna Karenina, Catherine Earnshaw, Dido. No-one read her any Keats, or watched East Enders with her. or encouraged her to express her feelings through her voice, writing, art of music. Obviously, we don't know if any of this would have helped - but when you think of how normal it is for anguished young people to pour out their feelings in (usually) rather dreadful poetry, the contrast is striking. For people with profound learning difficulties, of course, we have little idea how empathy and imagination might be stimulated; but engagement with powerful symbols of loos and longing seems a good place to start.

A third argument is, as Barbara Hardy (1968) puts it, that "narrative is a primary act of mind". In other words, we are all engaged in our own stories. Storytelling about ourselves and other is the way we make sense of our existence. what is a story from the point of view of a person with profound learning difficulties? We might think of it as an event which has a beginning and an end. Beginnings and endings are highly salient to people so dependent on their senses and on contact with other people. The challenge for us is to make those 'stories' meaningful and memorable. We developed *Odyssey Now* as an approach to telling one of the oldest stories in the world in ways that would be accessible to the most profoundly disabled people we could think of. In the package, events are presented through a combination of music, visual art, smells and tactile stimuli, and always involve an interaction. A recent project undertaken by Jillian Gordon, a student at Jordanhill College, suggests that for some people at least, the project is effective n promoting engagement and participation.

All very well, I hear you say, but is it literature in any sense of the work? And in any case, why not just stick with presenting the basic story line from literature in other forms

that are not language based, and which we know can be directly experienced by people with profound learning difficulties - music, art and dance? Why be pretentious about it?

Our contention is that language can in fact be directly experienced. The two fundamental modalities of language (speech and sign) are physical expressions. We use our bodies to create language, and it is only recently in history that poetry was written down and read as a solitary activity, rather than heard and seen and shared. Spoken language is like music - it has rhythm and intonation, and it is finely textured. Understanding the meaning of a text comes not from decoding the syntax - but from feeling it in your bones (Heaney, 1995; Webb, 1990). That feeling is one that we can transmit directly to people with learning difficulties and we have been experimenting in workshops with doing just this, using poems that you can move to, vocalise with, have whispered into your ear, or hummed onto your back. For example, in Tennyson's *Song of the Lotus-Eaters:*-

There is sweet music here that softer falls
Than petals from blown roses on the grass,
Or night-dews on still waters between walls
Of shadowy granite, in a gleaming pass;
Music that gentlier on the spirit lies,
Than tired eyelids upon tired eyes;
Music that brings sweet sleep down from the blissful skies.
Here are cool mosses deep,
And thro' the moss the ivies creep,
And in the stream the long-leav'd flowers weep
And from the craggy edge the poppy hangs in sleep.

Feel how the voice gets more and more languorous as the lines get longer, and how the s-sounds and long vowels contribute to the sense of stillness and heaviness. As a contrast, take the urgent work rhythms of James Berry's *Diggin Sing:*-

Whai-O! Man, go-on O. Want like stone want ground Go man, go-on O. Push hard down to groan. Go man, go-on O. Know ground like seeker. Go man, go-on O...

Another approach to poetry is to provide illustration. James Berry again, Sunny Market Song:

*1st voice:* Coffee

Spiced chocolate

Ackee

White yam Yellow yam Juicy melon

Breadfruit Grapefruit Arrowroot

2nd voice: I want some cinnamon and tamarind, man

How does this poem work? By conjuring up images of what we can see, taste and smell. So let's provide the associations by creating a market stall with all of these rich contrasts, and using the poemm as the accompanying music. We can go further than this, and try

making metaphors concrete through illustration. For example, in Lord Byron's *The Destruction of Sennacherib* 

Like the leaves of the forest when summer is green That host with their banners at sunset were seen; Like the leaves of the forest when autumn hath blown, That host on the morrow lay withered and strown.

You can create the forest of living branches, and then blow them down, replacing them with bare twigs and a carpet of withered leaves. (This poem has the added bonus of wonderful rhythms). In Macbeth, Lady Macbeth advises her husband to deceive King Duncan (whom they plan to murder) by putting on a smiling face

Suppose the innocent flower But be the serpent under't

As one of the activities associated with this scene, we literally present students with a flower (suitably smelling) and dart a plastic snake outfrom under it. Does it work as a symbol? I'm not sure, but it's worth a try (see below!).

Teachers in several schools have been experimenting with poetry (see for example, Merrick & Brennan, 1993). In Kingsbury School, Wigan, students have written their own poems based on careful study ofnatural things. In Dame Evelyn Fox School, Sue Lund studied the poetry of the firs world war with her students, ending the project by viewing the poignant last episode of *Blackadder*. At the end of it, she spread a white sheet on the floor and sprinkled it with red poppies, creating a powerful visual symbol for the experience.

The message is to get in there and take some risks! You may end up doing things that seem a bit odd, or a bit silly. Some things will work brilliantly, and others will fall totally flat. Your colleagues may think you mad. But we can promise you a lot of fun!

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Nicola Grove City University

Keith Park Greenwich Visual Impairment Service Nicola Grove is writing *Literature for All* for David Fulton publishers - a resource book for teachers - and would like to hear from anyone who is using stories, plays and poetry with people with difficulties in language and learning. Please write to me at 86 Bedford Road, London N2 9DA

Workshops

Two workshops based on *Macbeth in Mind* and *Odyssey Now* will be run at the BILD Conference 15th-17th September.

A workshop on *Literature for All* will be run at the NASEN Special Needs Exhibition in London on Thursday November 6th. Contact NASEN on 01827 311500 if your are interested in going to it.

Note from Nicola and Keith

We had a really enthusiastic response from many people to the ideas for Life Quilts for people with PMLD's. Unfortunately sheer pressure of work has stopped us taking this much further, but we hope to do something about it next year!

Can you help?

Haptic Manipulation and Investigation Strategies in Children who are Blind and Functioning at an Early Stage of Development

As part of a current research project I am investigating early development of hand function in children who are blind and functioning at an early stage of development. In particular, the investigation seeks to address the issues relating to the nature, the causes and the variation in strategies of haptic processing of objects. The first phase of the project considers how a child becomes able to assess particular properties of objects using the hands i.e. shape, texture, size and weight, and the types of exploratory strategies that are used. The second phase will focus on possible approaches that may be used to develop this aspect of hand function and considers possible intervention strategies which may offer more efficient strategies for processing tactile information.

As part of the research, I am interested in establishing contact with professinals with an interest in this area of development with a view to sharing research findings and finding out more about current practice. I would also be grateful for information relating to any teaching packs that have been found to be of value in early development of hand functin with children in this population.

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# THE WHOLE PERSON WHO ARE WE COMMUNICATING WITH?

Keynote lecture at 'Communication for All' Luxembourg, June 18th 1997

This opening lecture does not pretend to be either scholarly or exhaustive. It is an exploration, a series of insights from the inside. I hope you will find yourselves at peace with what I say. But I also hope my words will challenge you. They are reflections, not from an exclusively educational approach, but also from my own experience of caring and being cared for. Since I became a 'special' educator I have discovered that the world is not divided into people with special educational needs and those who care for them, but that we are *all* human. We contain within ourselves a capacity to embrace life in its fullness. What we sometimes lack is the courage to enable other people to start doing it.

To communicate fully we must strive to meet people on their territory when their need is the greatest. If many 'special' people were able to talk or to write down what it is that they need most of all, I think they would say, "Talk to me". "Give me time to communicate with you". "Listen to what I need you to know".

Our starting point must be an ability to feel comfortable with ourselves personally and professionally. But I am human and I have to admit that my life was far less complicated before I accepted that good care and education meant addressing the needs of the whole person; body, mind and spirit. I also have to remind myself to practice the two essential components to good caring which I tell my students they should develop: competence and communication. Well meant kindness and compassion are not enough. Neither should learning be restricted to a collection of assessable activities. Opportunities should be open-ended and allow time to reflect upon experience, to explore feelings as well as ideas, to develop imagination as well as memory, to engage the whole of a person's being in the importance of what it means to be uniquely human in their own right.

# Gradually I have learned:

- \* to be responsive to the presence of others
- \* to establish an understanding of the unique quality of each person
- \* to be honest and sensitive
- \* to consider what I am trying to communicate and to try to imagine how the message might be understood
- \* to be aware and accepting of the full range of human emotions
- \* to be aware that my colleagues also live with the pressures and stresses of caring and educating.

We will not always feel in control of ourselves or our lives. What we can do is to accept our humanity and our own vulnerability. Becoming aware of the many facets of ourselves will help us to grow in confidence so that other people feel secure enough to express themselves. Just as the circles in a tree trunk make up the story of a trees growth, so all that has happened in our lives is never discarded. It is incorporated into the whole of a person.

Sometimes it seems unless professionals are able to offer solutions, they can do nothing. The medical professionals are taught from their student days that it is good to offer a cure. Teachers are encouraged to help their pupils to achieve academic success. Few of us have been trained in human skills. In the hospice, when I am feeling strong, I confidently play with the children and spend time with their parents and carers. On the days when I am not feeling so strong I seek the company of one of the nurses to stand alongside me because the reality of other peoples' pain is too much for me to handle alone. When a parent whose child has just died, trusts you enough to ask you to sit with her whilst they break the news

to relatives and make the funeral arrangements, you discover you are ill equipped professionally, so you draw on the best you have to offer - you do those things which being a mother and a grandmother have taught you.

In Great Britain we cannot pretend that we know all the answers. There are people who still value academic achievement more than recognising the contribution to society which each person has to make. A few years ago I was asked to raise money for a charity. One Saturday morning I took a collecting box and a large poster which the charity had given me, and I stood outside a busy shopping centre. The poster was a photograph of two young men. Both were about fifteen years old. One man who was called Michael was standing behind a wheelchair in which his friend Kevin was sitting. Kevin had the physical features of Down's Syndrome. The writing on the poster read "When Michael is 18 he is going to university. When Kevin is 18 he is going nowhere."

People gave generously to the charity but as the morning progressed, I became more and more angry. I heard comments about the 'tragedy of handicapped persons', and it was a 'pity people like Kevin had to grow up'. I was also told I was 'wonderful to work with him'. Mostly the people who donated money believed the words on the picture, that Kevin was destined to go nowhere. I do not think anyone went close enough to read the small writing which said "Education can give Kevin a chance"/ No one is going nowhere. Everyone is on a life journey. Often the journey will cover rough and stony ground and it will be fraught with difficulties but we own it to Kevin to travel alongside him and not to abandon him.

People on the margins of society have an urgent need for warmth and honest straightforward communication between themselves and those who choose to listen. Everyone has a story to tell. The fact that we may be familiar with the background is irrelevant. It is in the telling of someone's story that we meet people with whom we work and through listening to them that they meet us.

David was a wonderful man who was financially poor in a successful society. When I met him he had lost the one thing which remained his - his physical integrity. By the time he was admitted to the AIDS ward he was unable to speak because ulcers had developed where his teeth should have been. He had refused to be admitted to hospital, jealously guarding his independence despite a growing terror of choking to death. On Christmas Day 1995 he gave in and his partner brought him to us. The doctors all thought he would die soon but day after day he crouched on his bed, clutching tissues in one hand and a vomit bowl in the other, mercifully oblivious of the stench from his rotting flesh. We were not immune to the smell, and we longed to escape outside. We were unable to understand his mumbled words and knelt patiently beside his bed whilst he scribbled his thoughts for us to read. We admitted to each other that we wished his suffering could end, and yet, combined with the distaste was a deep love for this broken man. We learned to value his humour and to respect his courage and we grew accustomed to his face and glad that he felt safe enough to leave the privacy of his room. People muttered, "If he was a dog you would take him to the vet and have him put out of his misery". But David was not a dog. He was a man with AIDS and a mouth which was being eaten away by disease. He needed to live out is last precious days among friends and we liked to think that when he died, he did so secure in the knowledge that he was loved and cherished in a way he had never known before.

Anne has profound and multiple learning difficulties. Although she has impaired vision, her hearing is good and she has learned to use some sounds to communicate. With extensive surgery Anne may be able to sit unsupported, but she will never be able to walk. With help she is able to lean forward so that she can stroke the cheeks of people close to her, smiling and making long sustained 'ah' 'ah' sounds of pleasure. On a large piece of paper covered with dollops of

thick paint, she produces masterpieces of palm and finger painting. Despite her manifold disabilities she has a fierce determination to live. She has a most appealing impudent grin. Her teeth are crooked and her blue eyes squint at everything that happens around her. She has never shown any sign of self-pity; no complaining, whining or crying. If she were able to talk I believe it would be witty and sardonic. It seems impossible that such a fragile malformed body can contain such vivid spirit, so much determination to survive and to improve.

Anne has a special significance for all who work with her. One cannot encounter this little girl and indulge in a bout of selfishness.

Richard is ten years old. He was the most challenging child I have ever worked with. At the time he came to me he had just had his third birthday. His father was in prison and his mother had committed suicide. Richard had three brothers and four sisters. He was the only black child. He had few possessions save a very thick file which described how six foster families had failed to care for him. His assessment stated he had severe learning difficulties and violent behaviour which necessitated nursery provision in a special school. It was believed his behaviour was made worse because doctors had failed to find the correct regime of drugs to control his epilepsy.

There was no doubt he had behaviour problems. each morning he would storm into the room, look around him and sweep everything which was on a table or surface onto the floor with his arm. Pictures and displays were removed equally as quickly as he hurtled around the walls tearing at everything in sight. His self-esteem was very low indeed. He had failed to make relationships in his birth family and his foster homes. His experience had taught him to trust nobody.

At first he communicated with me from behind. I would sense he was standing close and sometimes he would pinch me or bite my thigh to tell me he was there. Gradually, he learned to attract my attention by standing with his face pressed against my back and his arms around my waist. He could not bear to look at me. Once, after nine months, he climbed onto my lap, spat in my face, pulled me towards him and shouted, "I hate you -cuddle me". After two years he moved class and he gradually learned although his behaviour was still unacceptable at times, that we valued him as a person. Sadly, ......he had a major seizure whilst he was climbing during a physical education lesson. He fell and he died in the arms of his learning support assistant.

Illness, impairment and disability have powerful meanings attached to them. Currently in Great Britain the dictionary definitions of the words sick or unhealthy include metaphorical meanings as in a 'sick joke' or 'an unhealthy interest'. 'Disabled' may mean 'incompetent' and 'valueless' in a society which overvalues 'doing' and undervalues 'being'. What does this communicate to children, young people and adults? Are we telling them all the odds are against them? It takes courage, determination and very hard work to provide care and learning opportunities which are worthy of being called excellent. Schools and caring places do not become successful communities overnight. The challenge lies in the way in which the ingredients are blended together or, to use another image, in the way in which the players in the drama relate to each other. Only then do we have 'Communication for All'".

Erica Brown Centre for the Study of Special Education, Westminster College, Oxford

# FUTURE FOCUS ... Developing Criteria for Assessing Quality in Provision for Adults and Children with PMLD

Quality matters, for children and adults with profound and multiple learning difficulties. Poor quality provision, poor quality learning, means maximum dependency, lack of control and incluence, and limited experiences and opportunities. Good quality provision, good quality learning, ensures a more independent, more interesting, satisfying and enjoyable life

Developing measures to use in judging success supports the promotion of high quality and accountability.

Many schools, colleges, day and residential centres pursue continued quality improvement rather than simply trying to maintain current performance. They seek to i mprove inputs and outcomes through planning, consultation with staff and learners, and implementing quality control and quality assurance systems.

Determining what constitutes quality and how to describe it is a first step in establishing systems to support monitoring and evaluation. Developing inhouse systems has the advantage of securing the ownership of the system by those involved in the development but their limited currency outside the institution or organisation inhibits the making of comparative judgements. Conversely, externally developed systems, such as those for which OFSTED is responsible, may be difficult for the practitioner to accept, but have the benefit of being widely known and understood and enable students, families, staff and others to measure one institution against another.

Education, health and personal social services have all been active in developing evaluation systems to enable those making provision at all levels, and those who receive it, to judge to what extent provision fails to meet, achieves or surpasses the standards set. Personnel in all the community services accept that they have responsibilit to the learner to ensure provision meets individual needs and to society for the efficient and effective use of scarce resources. The use of quality criteria enables them to demonstrate the success of their work and the recipients to hold them to account for what is provided.

The theme of the next edition of *PMLD-Link* focuses on the issues surrounding the setting and use of quality criteria in child and adult provisin. If you have experiences to share, comments to make, ideas to contribute for example, on practitioner development of criteria; on the implications of using criteria set by outside bodies; on deciding the focus for cirteria; or on any other related topic, then please write about it, and send it to Carol.

Joan Boucher

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Whose Choice? Contentious issues for those working with people with learning difficulties.

Edited by Coupe O'Kane, J. and Goldbart, J.

David Fulton Publishers, 1996, 143 pp, £15.99

ISBN 1-85346-363-9

This book has an unusual format which works well. Its contents focus on three contentious issues relevant to people with learning disability; these topics are sexuality, ageappropriateness and integration. Each is the subject of one of the three main sections which comprise the book.

Each issue is addressed by three separate contributions. The writers of the first two chapters of each section express differing or complementary views, and the author of the third chapter of each section aims to synthesise and discuss the issues raised. I found this a useful and original way of examining these challenging areas.

The book begins with an introduction by Peter Mittler which looks at self-advocacy, emphasising the need for parent-teacher collaboration in providing opportunities for choice and decision making. He promotes the view that schools should have a self-advocacy curriculum, which includes parents from the outset.

Part 1 of the book is entitled 'A Positive Approach to Sexuality for Whom?'. Maggie Bowen begins this debate by presenting a series of case studies which offer evidence of questionable practices and decision making on behalf of professionals dealing with issues arising from the developing physical maturity of young people with learning disability. Caroline Downs and Ann Craft follow this with an early account of their study which explores safeguards, strategies and approaches relating to the sexuality of people with PMLD. Their chapter, which encourages the reader to reflect upon their own attitudes to sexuality, is followed by an account by Ian McKinlay of parental concerns relating to puberty and sexuality of people with severe learning disability. As he notes, we are at the stage where it is easier to raise relevant questions than to answer them.

Section 2 goes on to consider age-appropriateness. Nind and Hewett provide an informed and considered critique of this concept. Their contribution is followed by a chapter by Porter, Grove and Park who advocate the utility of the approach, and provide examples of how to put it into operation in a sensitive way. These chapters are of high quality, both proposing means of extending choice available to service users. In her subsequent discussion of this debate, Beryl Smith appreciates the value of both

points of view, and extends the debate by reference to relevant research.

The final section of the book considers how far educational integration should be developed. Hall expresses his frustration at the present special school system, which he describes as segregationist and too influenced by the medical model of disability. I might have felt more comfortable with his trenchant style if he supported his statements with more evidence and did not refer to special school pupils as though they were all male. Conway and Barker are much more cautious in their approach, calling for more rigorous research to critically evaluate the outcomes of integration programmes. An evidence-based approach is, of course, essential, although I was left wondering whether integrated programmes are not being called upon to meet standards not required of the special school sector. In the final chapter, Peter Farrell considers both views, and proposes a compromise in the form of special units in mainstream schools.

This book emanates chiefly from education-focused professionals of different backgrounds. Although its sub-title refers to *people* with learning difficulties, there is more emphasis on the school sector, than there is on adult services. Perhaps this reflects the book's target audience. It is a measure of the book's success that I would have liked it to go on to include a critical examination of the

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current pattern of service delivery to adults with severe and profound learning disabilities.

Judith Cavet is Principal Lecturer in Social Work at Staffordshire University.

Home at Last – how two young women with profound intellectual and multiple disabilities achieved their own home.

Fitton, P., O'Brien, C. and Willson, J.

Jessica Kingsley Publishers, 1997, 190 pp.

ISBN 1-85302-254-3

'No-one would wish to argue that the potential of people with multiple disabilities to participate in the community has been fully realised. Indeed in some parts of the country a view persists that a congregate residential setting staffed by nurses is an appropriate form of provision, with many people languishing on the wards of long-stay hospitals or in nursing homes.' (Foreword).

Home at Last provides not only an antidote to such pessimism, but a practical demonstration and guide to how a home can be established and run for adults with profound and multiple disabilities. Those colleagues who are familiar with Pat Flitton's previous book, Listen to Me—communicating the needs of people with profound intellectual and multiple

disabilities, will open the pages of this co-authored book confident that the story will challenge all those who care for people with PMLDs.

Written with both professional and personal insight, *Home at Last* combines a powerful and yet often disturbing narrative where a balance has been struck between the desirability of giving the women choice about their activities, the clothes they wear and the food they eat, and the recognition of their limited ability to communicate their choices.

Throughout the book, everyday routines are described realistically and sometimes the reader has to pause to remember that shopping, cooking and laundry were done *for* the women rather than *by* them.

In a rapidly changing world, where the potential of people with learning difficulties and the contribution which they make is more often forgotten rather than celebrated, the book is a powerful reminder of empowerment and entitlement.

I was particularly impressed by the chapter concerning bereavement and replacement which is brave enough to address the topic, suggesting that carers as well as clients need support and understanding when sad things happen.

If I have any reservation about this book it is that over half the text consists of appendices which give very detailed accounts of care packages, budgets, house plans etc. Although very specific to the experiences of the authors, these do however provide a framework worthy of consideration for others who may contemplate Flitton, O'Brien and Willson's venture.

Erica Brown is B. Phil Course Leader at the Centre for the Study of Special Education at Westminster College, Oxford.

Crossing the Bridge I and II—access to the National Curriculum for pupils with profound and complex learning difficulties.

Kent Curriculum Services Agency and Kent County Council Education Support Services, 1995 and 1996.

For details of how to obtain copies of *Crossing the Bridge* contact:

Grange Park College, Birling Road, Leybourne, Kent. ME19 5QA

Telephone: 01732 842144 Fax: 01732 848004

When the National Curriculum was first introduced, many teachers working in special schools felt that, whilst the concept of a National Curriculum for all pupils was acceptable and even useful, as it stood it began at a point on the continuum of learning and development that was far too high for their pupils. Some teachers called for the production of levels to

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precede Level 1, to enable the work that their pupils were doing and the achievements that they were making to be recognised and acknowledged within a curriculum that claimed to be a curriculum for all.

In 1995 and 1996 a group of teachers of pupils with profound and multiple learning difficulties (PMLD) from special schools in Kent produced documents that would 'bridge the gap' between the type of activities that they felt to be appropriate to their pupils and Level 1 of the National Curriculum.

As we noted in the previous issue of *PMLD Link*, the Crossing the Bridge booklets use the structure and format of the National Curriculum and detail the pre-requisites necessary to access Level 1 in the subjects of English, mathematics, science, history, geography and information technology. As well as describing the stages that exist between the achievements of pupils with PMLD and the beginning of the National Curriculum, these booklets also include programmes of study that offer suggestions as to how the various attainment targets can be made more accessible to pupils with PMLD, and lists of resources that can support the activities suggested.

Crossing the Bridge certainly does offer a clear and detailed framework for the targeted subjects of the curriculum for pupils with

PMLD. By following the structure and terminology of the National Curriculum (unfortunately pre-Dearing in the case of English, maths and science, although I don't think that diminishes the value of the document in its own right) these materials help teachers to view the curriculum for pupils with PMLD in the same terms as the rest of the school population and to comply with legal requirements. The statements of attainment begin at an appropriate level for pupils with PMLD and provide a logical, consistent and detailed, yet not unwieldy, progression to Level 1. These steps alone are useful to help teachers plan 'where to go next' in each area of their pupils' development. However, it must be remembered that children with PMLD in particular do not follow a neat line of progression as they develop and progress may appear quite patchy, random and diverse. The documents should therefore be used flexibly as an aid to planning an individual programme for each child rather than followed slavishly. The starting point for planning should always be the child rather than a document.

The examples of behaviours that may indicate achievement for each attainment target are useful in helping teachers to assess current functioning and may also help some teachers to understand why their pupils may be behaving in a particular way. The ideas

given in the programmes of study are invaluable sources of ideas for daily planning in each of the subjects at the appropriate level and the excellent and very comprehensive section on resources would be of great value to most schools, especially those trying to build up a bank of appropriate resources. Addresses of where to obtain the resources are also provided.

I would recommend Crossing the Bridge to any school as an aid to curriculum planning which offers a useful hierarchy of development and skill acquisition alongside useful ideas for accompanying activities and resources, set within the framework of the National Curriculum. I would not like to see it used as a form of assessment, a checklist against which children's progress could be measured, or as a whole curriculum which ignored the individual needs and abilities of each child in each area. However, it does provide a document that shows teachers how to teach the subjects of the National Curriculum to children with PMLD and helps them to understand and appreciate their progress in National Curriculum terms.

Suzanne Saunders lectures at the Centre for the Study of Special Education at Westminster College, Oxford.

#### **BOOKS**

Solving Children's Sleep Problems: A Step by Step Guide for Parents by Dr. Lyn Quine published by Beckett Karlson (1997)
ISBN - 901292 01 0
Price 12.99

Whose Choice? Contentious issues for those working with people with learning difficulties edited by Judith Coupe O'Kane and Judith Goldbart (1996)
This book is reviewed in this issue of PMLD-Link. It is published by David Fulton ISBN 1-85346-363-9
Price 15.99

Home at Last - how two young women with profound intellectual and multiple disabilities achieved thier own home by P. Fitton, C. O'Brietnand J. Wilson. Published by Jessica Kingsley Publishers 1997 ISBN 1-85302-254-3

Crossing the Bridge I and II - Access to the National Curriculum for pupils with profound and complex learning difficulties devised by a consortium of teachers and published by Kent Curriculum Services Agency and Kent County Council Education Support Services 1995 and 1996

Available from Grange park College, Birling Road, Leybourne, Kent ME19 5QA

Forgotten Lives: Exploring the History of Learning Disability edited by Dorothy Atkinson, Mark Jackson and Jan Walmsley and published by BILD Publications (1997) ISBN 873791 4 4

Families in Context: Emerging Trends in Family Support and Early Intervention edited by Barry Carpenter and published by David Fulton Publishers (July 1997) ISBN 1 85346 489 9 Price: £12.99

Focus factsheets are a series of leaflets for staff working with people with visual and learning disabilities. They cover a variety of topics., Available now, or very shortly are:

Looking for Hearing problems in people with learning diffiuclties

Glasses for adults with severe learning difficulties

Planning individual leisure activities for adults with visual and learning disabilities

Focus Catalogue up to and including Focus 19

For further information contact RNIB, 224 Great Portland Street, London W1N 6AA Tel: 0171 388 1266

RNIB is now producing a new current awareness service about new publications in the field of visual impairment with a range of other information. Details from RNIB 224 Great Portland Street, London W1N 6AA Telephone: 0171 388 1266

**PLANET** has produced a range of publications on play and leisure for children, young people and adults with disabilities. They include:

Set of Seven Play Leaflets price £3.00 per set

Product Leaflets price 50p. each

Resource Leaflets price £1.00 each

Video Lists in two volumes. Price: Vol.1 £4.50; Vol. 2 £5.00

"Whole Services for Whole People" Leaflets price 75p. each

Suppliers List, price 75p.

Journalds, Magazines and Newsletter List, price 75p.

Posters: Images of a Movement 0 Liberty, Equality, Disability by David Hevey. Price £9.00 per set

Further information from PLANET, Cambridge House, Gambridge GRove, London W6 0LE Tel: 0181 741 4119

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Set of Seven Play Leaflets price £3.00 per set

Product Leaflets price 50p. each

Resource Leaflets price £1.00 each

Video Lists in two volumes. Price: Vol.1 £4.50; Vol. 2 £5.00 "Whole Services for Whole People" Leaflets price 75p. each

Suppliers List, price 75p.

Journalds, Magazines and Newsletter List, price 75p.

Posters: Images of a Movement 0 Liberty, Equality, Disability by David Hevey. Price £9.00 per set

Further information from PLANET, Cambridge House, Gambridge GRove, London W6 0LE Tel: 0181 741 4119

#### COURSES AND CONFERENCES

**SEPTEMBER** 

9th Practical Workshops

and Two workshops can be chosen each day from a range of themes: Taking

10th control; Multisensory work; Gardening and cookery; Alternative communication; Basic

Literacy and numeracy; Whole body activities; Life skills; Developing Interaction.

Run by: Orchard Hill FE College, Carshalton

Venue: Orchard Hill FE College Further details: Andrew Lindup

Tel: 0181 770 8125 Fax: 0181 642 3763

14th **bild** International Conference 1997 Services challenged by complex needs?

to The conference will focus on complex needs and learning disability. Specific 17th research interests and areas of professional good practice will be identified.

Venue: Manchester
Further details: Karen Clarke

BILD, Wolverhampton Road, Kidderminster DY10 3PP

Tel: 01562 850251

15th <u>Aromatherapy</u>

and The benefits of using aromatherapy with people with learning disabilities.

16th Run by: Playtrac Tutor: R.D. Mugan

Venue: Horizon NHS Trust, Harperbury, Herts

Further details: roc

Tel: 01923 663628

23rd "Tuesday Training"

Introduction to visual disability in people with learning disabilities including guiding techniques and environmental considerations and adaptations.

Run by: Multiple Disability Training Service

Venue: London

Further details: Multiple Disability Training Service

Tel: 0121 643 9912

**OCTOBER** 

8th Stimulating the senses

Run by: roc

Venue: Horizon NHS Trust, Harperbury, Herts

Tutor: Deborah Davies Further details: roc

Tel: 01932 427 385

11th Sherborne Developmental Movement - Level 1

Run by: Sherborne Foundation

Venue: Bristol

Further details: Cyndi Hill.

Tel: 0117 937 3647

14th <u>Assessing Communication</u>

Run by: roc

Venue: Horizon NHS Trust, Harperbury, Herts

Tutor: Charlotte Wilmer

Further details: roc

Tel: 01923 663628

17th Music and Communication - Music for Non-Musicians

Run by: RNIB Venue: Birmingham

Tutors: Mark Gray and Simon Labbett

Further details: Simon Labbett

Tel: 0171 388 1266

**NOVEMBER** 

3rd Music and Communication - Music for Non-Musicians

Run by: RNIB Venue: Bristol

Tutors: Mark Gray and Simon Labbett

Further details: Simon Labbett

Tel: 0171 388 1266

6th <u>Dance Dynamics</u> and Run by: roc

7th Venue: Horizon NHS Trust, Harperbury, Herts

Tutor: Wolfgang Stange

Further details: roc

Tel: 01923 663628

7th <u>Challenging Behaviours</u> and Run by: INTERACT

8th Venue: Wythenshawe Hall, Manchester

Leader: Dave Hewett

Further details: Helen Janes

Tel: 01727 768726

8th Sherborne Developmental Movement - Level 1

Run by: Sherborne Foundation Venue: Exmouth, Devon Further details: Bill Richards

Tel: 01395 270 603

8th The same course is being run at Winchester

Further details: Janet sparkes

TEI: 01962 855 168

15th <u>Sherborne Developmental Movement - Level 1</u>

Run by: Sherborne Foundation

Venue: Wren Spinney School, Kettering Further details: Stephen Curllingford-Agnew

01536 481939

17th Music and Communication - Music for Non-Musicians

This is a repeat of the course on 13th October

19th <u>Differentiation: Including Pupils with PMLD</u>

Run by NASEN

Venue: London (exact venue to be confirmed)

Further details: NASEN

Tel: 01827 311 500 Fax: 01827 313 005

25th Active Listening Skills

Run by: roc

Venue: Horizon NHS Trust, Harperbury, Herts

Tutor: Andy Battell Further details: roc

Tel: 01923 663628

26th The Triangualr Relationship

Run by: roc

Venue: Horizon NHS Trust, Harperbury, Herts

Tutor: Noelle Blackman Further details: roc

Tel: 01923 663628

**DECEMBER** 

8th Music and Communication - Music for Non-Musicians

This is a repeat of the course on 3rd November

11th Relaxation

> Run by: roc

Venue: Horizon NHS Trust, Harperbury, Herts

Tutor: **RD** Mugan Further details: roc

> Tel: 01923 663682

16th Introductin to Invensive Interaction

> Run by: roc

Venue: Horizon NHS Trust, Harperbury, Herts

Andy Battell Tutor: Further details: roc

> Tel: 01923 663628

**JANUARY 1998** 

13th Assessing Communication

> Run by: roc

Venue: Horizon NHS Trust, Harperbury, Herts

Tutor: Charlotte Wilmer

Further details: roc

> Tel: 01923 663628

15th Starting MOVE

and Run by: Move International

16th Venue: Gorway Centre, University of Wolverhampton

Jenny French and MOVE International trainer Tutors:

Further details: Move International

01902 323066

**FEBRUARY** 

12th **Aromatherapy** 

Run by: and

Venue: Horizon NHS Trust, Harperbury, Herts 13th

> Tutor: R.D.Mugan Further details: roc

> > Tel: 01923 663628

24th Stimulating the Senses

Run by:

Venue: Horizon NHS Trust, Harperbury

Tutor: Charlotte Wilmer

roc

Further details:

roc Tel:

01923 663628

26th Drama for People with Profound Learning Disabilities

Rn by:

roc

Venue: Horizon NHS Trust, Harperbury, Herts

Tutor: **Deborah Davies** 

Further details: roc

Tel:

01923 663628

MARCH

Differentiation: Including Pupils with PMLD 4th

Run by: **NASEN** 

Venue: Manchester (exact venue to be confirmed)

Further details: NASEN

Tel: 01827 311 500

01827 313 005 Fax:

4th Art - the vlaue of mark making

Run by: roc

Venue: Horizon NHS Trust, Harperbury, Herts

Tutor: Irma Mullins Further details: roc

Tel: 01923 663628

12th Introduction to Observation and Recording Skills

Run by: roc

Venue: Horizon NHS Trust, Harperbury, Herts

Tutor: Deborah Davies Further Details: roc

Tel: 01923 663628

#### DISTANCE LEARNING and INDEPENDENT STUDY

A series of distance learning courses are being developed by BILD including:

Positive Approaches to Challenging Behaviour

For staff working with people who present challenging behaviours

Have a Good Day

For staff working in day services

Ageing Matters

For staff working with older people

Better Choices - Fuller Lives

For staff working with people with profound learning disabilities

Further details from BILD, Wolverhampton Road, Kidderminster, Worcs DY10 3PP

Telephone: 01562 852251

# **EXHIBITIONS and EVENTS**

26th Independent Living Exhibition (Supported by Naidex)

to Run by: Reed Exhibitions

27th Venue: Doncaster Exhibition Centre, Doncaster Sept. Further details: Reed Exhibition Companies

Tel: 0181 910 7873

1st Horticultural Therapy's Second Midlands Flower Show October Venue: HT Ryton, Ryton-on-Dunsmore, Coventry

Further details Horticultural Therapu

Tel: 01373 464782

# SCOPE Leisure Resource Centre OPEN DAYS

Permanent displays of play, sport and craft equipment, with library, and video collection. On open days there will be demonstrations and a range of activities for people to participate in, including adapted games, music and art activities.

Dates: Tuesday 16th September; Saturday 11th October; Wednesday 12th November;

Tuesday 2nd December

Venue: Scope Leisure Resource Centre, Redditch Furtrher information: Nick Lee or Lesley Butcher

> Tel: 01527 550909 Fax: 01527 550808