

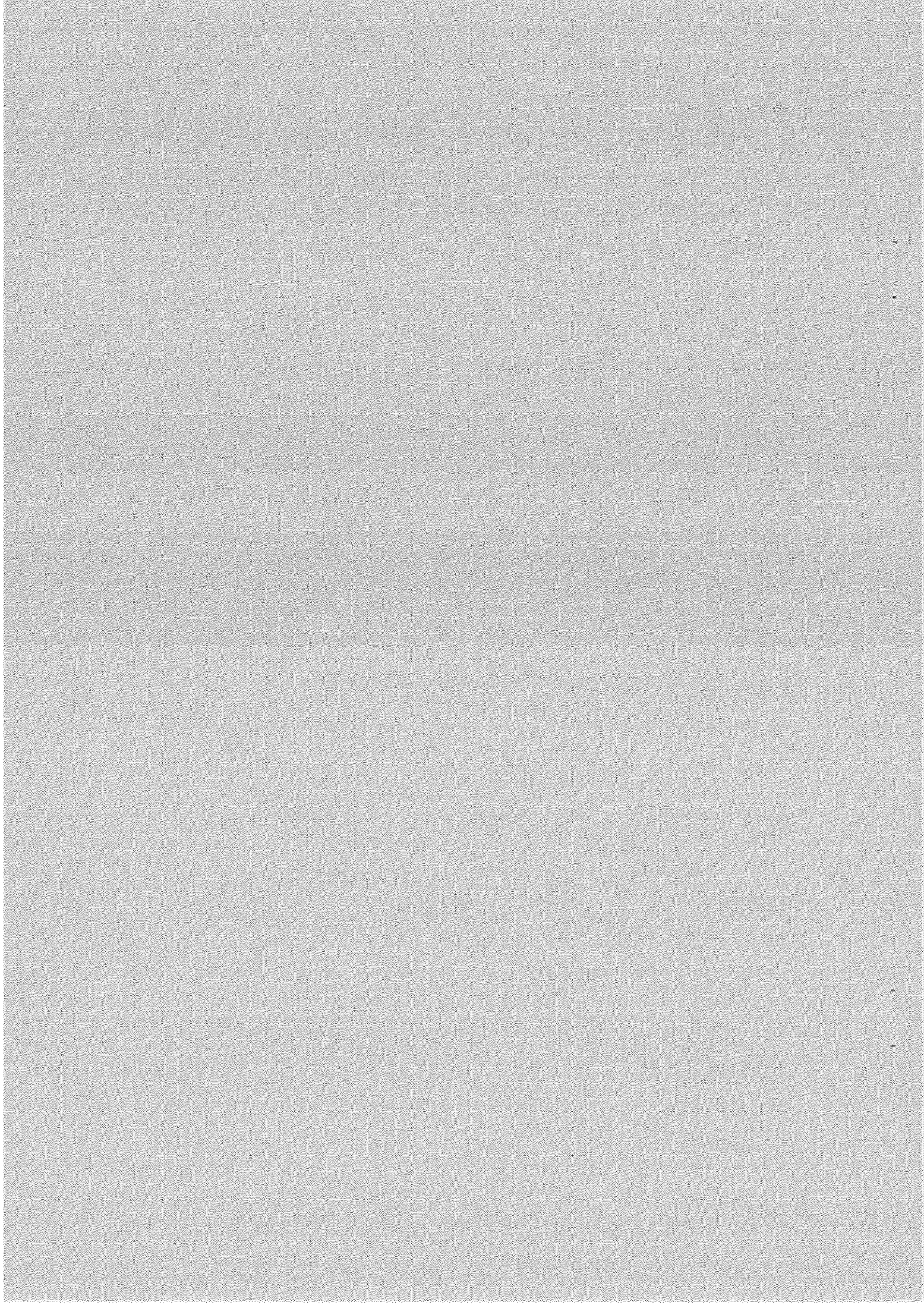
PMLD LINK

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

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PMLD LINK relies on contributions from practitioners, parents, carers and everyone interested in this field



As you can see (or feel!) the topic for this issue has attracted a record number of articles. Many of these are from people who work in schools which is predictable, considering the emphasis on literacy in the curriculum, but many of the ideas and practical examples are adaptable for children and adults in other settings. A number of articles are relevant to people of all ages while some specifically have adult listeners and readers in mind. I hope this wealth of ideas and perspectives will encourage people to 'have a go' if they have not already done so. It is particularly appropriate in this issue that we have not only text, and illustrations, but also a poem. Does this trigger *your* imagination? How about some more to liven up future issues!

Once again, many thanks to all contributors who are willing to write for us and who often make huge efforts to get items to me in time to be included in this issue. However, the discussion is not closed with this issue. If you have an article 'bubbling under' about literature or drama, or comments about anything you have read, here or anywhere else, send it in for the next issue.

In **Report Back** we have an account of the Mencap PIMD seminar on *Lifelong Learning*. Opening with an introduction by Penny Lacey to the Reading for All pack, the rest of the seminar focused on some of the issues in continuing education, and the changes suggested to the system of funding for post 16 education. Also included is the first Newsletter about the project '*Enhancing Quality of Life*' and we hope to be able to keep readers up to date with this project in future issues.

This issue includes a **news** section - something to celebrate! If you have any news items for the next issue do let me know - a paragraph is enough just to keep readers up to date with what is going on elsewhere.

The topic for the next issue is *Multisensory Environments* - we need your views whether good, bad or indifferent! We would like to hear about how you use them, what you have used and how, how successful they have been, any words of caution and any great enthusiasms. We would like to hear if your child, pupil or client has particularly benefited from using a multisensory environment. Tell us about it, please! I hope that Jill Porter and Olga Miller's introduction to the topic in **Future Focus** will trigger your ideas - if so, write them down and send them to me!

BUSINESS MATTERS

Subscriptions

First of all an apology to all of those subscribers in the UK who were sent a subscription form for subscribers in Ireland. This did cause a lot of confusion, and I apologise for this error. For those of you who have not managed to sort this out and have not resubscribed because of it, there is a subscription on the back page of this issue, as usual. I do hope this will not put you off renewing your subscription. If you are going to resubscribe, please do so as soon as possible, as this is the last issue which will be sent to those of you who have not subscribed for 1999/2000.

Articles

Articles or any other material for the next issue should reach me by the end of April. They can be sent by post or e-mail to the following address:

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Sensory Storytelling: A Resource for People with PMLD

The project on Sensory Storytelling was borne out of the concept known as 'Tactile Stories' (Fuller 1990). Bag Books is the name of the company which makes and sells Tactile Stories. Sensory storytelling adopts the principles of tactile stories and builds upon the personal aspect of stories, which can play an important role in storytelling.

Bag Books/Tactile Stories were borne out of Chris Fuller's work with tactile discrimination cards (Fuller 1999). To entertain a small group of pupils one day, she began to invent an amusing story based on a series of cards and, as she reports, "to my amazement the children were immediately caught up in the intimate atmosphere created by story telling". Fuller (1999 20).

Tactile Stories and Sensory Stories do not look like conventional books because the pages are made of plain, high quality card and are not bound together, but stored in boxes. Each book usually comprises 6-8 pages, each page having an accompanying sentence. Each page contains a sensory stimulus, and nothing else. The sentences are written on the reader's card, so that the pages of the book are not too confusing for people with visual impairments and/or learning difficulties. The reader reads a sentence and produces the stimulus, which is attached to the appropriate 'page'. The reader reacts to the stimulus and then passes the page to the listener and encourages him or her to do the same. The sentences, although relatively short, are read from a card to ensure consistency. It is only through consistent reading of the story that listeners will be able to familiarise themselves with the stories - recognition of the sentence structures can lead to anticipatory responses when exposed to the stimuli in the future.

One of the reported traits of 'good literature' is that the characters become real to the reader, so that the reader can relate, in some way, to events and responses in the book. In relation to this aspect of 'good literature', books can be written on a variety of levels where the relationship between the reader and the character(s) can be placed anywhere on, or indeed can move along, the implicit-explicit relation continuum. In developing Sensory Storytelling, an explicit relation between reader and character has been employed to the extent that the focus of the story is placed on the reader him or herself engaging in an action which is particularly enjoyable and particularly memorable. For example, Elaine particularly enjoys adapted bike riding, so her story focuses on a bike ride in a local park where Elaine has ridden in the past. Jenny wanted a more educational story for their son, Craig, and since he had just become an uncle for the first time, she constructed a story around the pregnancy and the birth of baby Sophie.

The concept of personalisation of the stories is enhanced by the use of accompanying 'photo stories'. The photographs are enlarged to A4 size and are stored in adaptable ring binders which can be used as stands to display the photographs. The first three pages comprise the Makaton symbol, Makaton sign, and the word which indicates the chosen story. The remainder of the 'photo book' contains photographs of the central character engaging in the specified activity. For example, Craig's photographs of the central character show him visiting his pregnant sister-in-law and feeling her stomach, receiving a telephone call to let him know that he had become an uncle, travelling by car to visit his new niece, visiting her in hospital, and so forth. This helps to personalise the story further, and may even help to enhance memory and understanding.

Another important aspect which has been developed as part of the Sensory Storytelling project is enabling choice. Before each story is read, the opening pages of the photo story are used to convey the Makaton sign and symbol and the word for the story (eg. Elaine's word is

'bike' and Craig's word is 'baby'). Through repeated association with reading the story, it is anticipated that people with PMLD may eventually sign, or communicate through adapted signing, the story of their choice. This is a relatively complex task, but it is also possible to convey a desire for a particular story through a response to someone else signing the relevant word.

Expected outcomes were realised - four books, which were placed in a library resource for parents and carers to borrow. In addition, several of the young people involved have made progress with specific abilities since beginning to read their stories on a regular basis. One striking example is of a young woman who has learned to engage in the blowing action. Indeed, her school has noted several improvements in her abilities since becoming involved in the project.

Many unexpected positive outcomes were also noted. What was particularly apparent throughout the course of the meetings was that members of the small working group formed strong friendships and often remained behind to talk to one another at length long after the meetings had finished. This naturally gave rise to information networks - particularly since the four mothers who formed the working group came from three different local authorities. *

Dissemination enabled enhanced local and national awareness of the project, and the opportunity for participation in community events. For example, one local authority within the region invited the working group to present Sensory Storytelling to the general public in celebration of the 'Dundee Reading Week' which formed part of the National Year of Reading celebrations. This event was successful and enjoyable for all concerned; it was attended by parents, teachers and therapists. In another local authority one mother was asked to deliver in-service training at her son's school - they were so reluctant to return his story to him, but eventually decided that other people might benefit from having their own personal stories. Dissemination has been on a national basis and enquiries have been received from all over Britain. All those interested are invited to contact PAMIS for further information.

The strong working relationships and friendships within the group has given birth to a new project - an exploration of using poetry in a variety of different ways. This project is in its infancy -

but watch this space!

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* The Sensory Storytelling working group consisted of four parents of people with PMLD and the Leisure Development Worker in PAMIS (Profound and Multiple Impairment Service). Meetings took place approximately every four weeks, and the project ran for almost one year.

READING OBJECTS: LITERACY AND OBJECTS OF REFERENCE

Introduction

Alberto Manguel, in his book 'A History of Reading' introduces his subject with the following eloquent paragraph:

"The readers of books.....extend or concentrate a common function to us all. Reading letters on a page is only one of its many guises. The astronomer reading a map of stars that no longer exist; the Japanese architect reading the land on which a house is to be built so as to guard it from evil forces; the zoologist reading the spoor of animals in the forest; the card-player reading her partner's gestures before playing the winning card; the dancer reading the choreographer's notations, and the public reading the dancer's movements on the stage; the weaver reading the intricate design of a carpet being woven; the organ player reading various simultaneous strands of music orchestrated on the page; the parent reading the baby's face for signs of joy or fright, or wonder; the Chinese fortune teller reading the ancient marks on the shells of a tortoise; the lover blindly reading the loved one's body at night, under the sheets; the psychiatrist helping patients read their own bewildering dreams; the Hawaiian fisherman reading the ocean currents by plunging a hand into the water; the farmer reading the weather in the sky - all these share with book-readers the craft of deciphering and translating signs."

Manguel concludes: "We all read ourselves and the world around us in order to glimpse what and where we are. We read to understand, or to begin to understand. We cannot do but read. Reading, almost as much as breathing, is our essential function" (Manguel, 1996, pp 6-7). So how do we learn to read 'signs'? More specifically, how do we learn to read objects? In the first part of this paper I discuss objects of reference, and in the second I describe two types of 'reading objects.'

Objects of reference

The term objects of reference refers to the use of objects as a means of communication, and was first described by Jan van Dijk in the mid-1960s as a means of communication for people with congenital deafblindness. A review of this literature *How Do Objects Become Objects Of Reference* (Park 1997a) also discussed the importance of a theoretical model of object use. This is because most of the literature is concerned with the use of objects of reference with children and adults who are already communicating intentionally. There is very little literature on the use - and the relevance - of objects of reference with *individuals with profound and multiple learning disabilities who are not communicating with intent*.

The literature review identified one particular issue in the use of objects of reference with people with profound and multiple learning difficulties in that the objects of reference - chosen by teachers or therapists to represent significant activities, objects, or people - may be *representational*. In other words, the objects may stand for, or represent, something other than themselves: a purse or wallet for shopping, a piece of material to indicate the sensory room etc. Using objects of reference may appeal to *us* because *we* think they have a 'common sense' value: they are permanent, manipulable, and concrete, and their use should therefore not be problematic. Most of the literature reviewed, however, suggests using them in a way that

pre-supposes that the user understands the distance between vehicle (the object itself) and referent (the concept to which it refers). For example, why should a purse represent or 'stand for' shopping? How do we know what an object may or may not 'mean' for someone else? Using the language of Alberto Manguel, we might ask: how do we know what someone else is reading? Re-phrasing it we can ask: how do objects acquire meaning for each individual?

This can be illustrated by the following description of two teenagers, Alex and Anna, and their communication needs. Pre-intentional communication may be described as being idiosyncratic, context-dependent and individually directed. Alex, who is 16 and does not communicate with intent, has been observed by his carer, at dinner times, to 'flutter' the fingers of his right hand, a behaviour that the staff who know him best have interpreted as meaning 'This is nice/I like this/I am comfortable with this.' This behaviour is, in one sense, unique to Alex, and so it is *idiosyncratic*; it only ever occurs at dinner times and so it is *context-dependent*. It is not intentional communication because Alex is not *deliberately* transmitting a message, although the staff are skilled in responding to the behaviour as if it was intentional. This is a result of their efforts to communicate with Alex: he has been encouraged to feel the plate and spoon, smell the food, listen to the carer talk to him and allow him time to respond in his own individual way. In this way the communication is *individually-directed* in that it aims to help him make sense of his environment.

The final stage of intentional communication - when people begin to use words, signs, symbols, objects or any other communication media - can be described as *conventional, context-independent* and *socially directed*. For example, Anna, also 16, is in a school leavers group. All of the teenagers in her group have a severe visual impairment and severe learning difficulties. The group shares an objects of reference board that indicate school activities, school personnel, and school rooms. The system of objects of reference has been developed to be the same for all the group (*conventional*), it is used across home and school environments (*context-independent*) and one of its aims is communication between the members of the group (*socially directed*). Anna's objects of reference, and those of her peers, include an audio tape case stuck on a piece of card for 'leisure time' (after dinner when the students stay in their classroom and play their own choice of music); a crushed can on a piece of card for the current project (crushing cans for an ecology project); a guide cane for 'walking/mobility training'; a purse for shopping (this is also stuck on a card and is not used in the activity); a bus ticket on a piece of card for 'going on the bus.' These *shared objects of reference* are in contrast to Alex's *individualised objects* which include: a spoon for cooking (the same one he is helped to use in stirring the various mixtures); an armband for swimming (the same one he wears in the hydrotherapy pool).

In Alberto Manguel's analogy, Anna is already a fluent reader, whereas Alex is learning to read. It is possible to extend this analogy to suggest that, because of this, they need different texts to support and develop Anna's and Alex's different skills of reading. What would happen to them if they attended the same school where a standardised use of objects was being used? Would they both be given a plastic model of the Eiffel tower to represent Modern Foreign Languages? Or would the Eiffel tower be better for Geography?! I would suggest that we need to re-consider what we claim to be doing in the name of communication.

When we ask ourselves how we might choose an object of reference for someone who does not communicate with intent, we are asking the wrong question. A more appropriate question is: *How may Alex learn to 'read' objects?* In other words, how may his objects become objects of reference? Marian McClarty describes how 'the spoon as object of reference in the child's hand is more than a symbol, more than a label, is a component of the whole activity of eating

and will remain part of the whole activity for the child for quite some time before it is readily identified as a symbol for a meal' (McClarty, 1995, 1,40). This statement contains an important point - to begin with, a spoon is just a spoon. We concentrate too much upon the choice of an object of reference, rather than the developmental process in which an object *becomes* an object of reference. As Sigmund Freud is famously supposed to have remarked: 'sometimes a cigar is just a cigar.'

We need, therefore, to reflect upon our practice and to develop a theory of object use - it might also be called a theory of object literacy. Many of us might feel uncomfortable when discussing issues from a theoretical perspective, but I would argue that it is essential - and especially if we do feel uncomfortable about it. Many teachers, and perhaps therapists, may feel that some academics within their field of work are too removed from practice. This may be so, but an academic might justifiably reply by saying that practitioners are anti-theoretical. Some time ago I was invited to give a presentation on the use of objects of reference, and just before I was due to start the organiser told me quite emphatically: "this is a practical workshop that provides practical answers to practical questions. We don't want any theory or funny business like that". I ignored the comment and carried on regardless - and, of course, people were quite happy to discuss theory that is concerned with improving practice. Marion McClarty warns us of the danger of objects of reference becoming 'window dressing' in our classrooms, and argues: "The problem for those wishing to make effective use of this method, however, is first to gain enough information as to the theoretical basis of the methodology and then to translate this into a meaningful approach in their own context" (McClarty 1995, 38-39). This vital statement is clearly a far cry from giving out bags of Nachos and calling it a Spanish lesson.

Reading objects (I): daily activities

When considering the use of objects within everyday situations with someone who does not communicate with intent, it may be helpful to consider the 'MMF' principle (Park, 1997b). This refers to choosing and using objects in naturally occurring contexts that are *meaningful, motivating and frequent*. Here are six real examples, two from each category, that illustrate that objects need to be relevant to the individual user and *not* to the therapist, teacher or inspector.

Meaningful

Daniel does not communicate with intent; he is blind and, until a few months ago, was extremely tactile defensive. Instead of selecting 'objects of reference' for school activities, Daniel's teacher and speech and language therapist looked at the ways in which Daniel's functional use of objects could be developed throughout the school week. Using a spoon for dinner and a cup for drink were the first two obvious choices; in addition they chose a flannel for 'washing my face'; a toothbrush for 'cleaning my teeth'; helping to put on and take off his coat for 'going out' and 'coming in'; holding the register on his lap while he and a support assistant returned the register to the office each morning; holding an audio cassette on the way to the hall for movement and helping to put the tape into the tape recorder. Daniel is helped to use these objects in context, and is now holding objects for over two minutes before throwing them. He demonstrates an understanding of the routines to the staff who know him best by his relaxed manner. In this way, Daniel is learning to read objects.

Angela does not like to sit down and this made school life very difficult for the class staff. One day, when they had managed to persuade Angela to sit down, her teacher gave her a string of beads, and Angela sat at the table with the others for nearly 15 minutes. This was quite a breakthrough, and so, building on this success, Angela was given the string of beads

every time she was expected to sit down with a group. After a while, Angela was persuaded to leave the beads on the back of the chair and to participate more in the group activity. This strategy has been very effective, and the string of beads - for Angela - means something like 'sitting down with the others and doing things'. Angela's teacher can then differentiate the activities in her teaching file according to the National Curriculum subjects. When the activity is finished, Angela is encouraged to drop the beads into a small cardboard box - to indicate 'finished' - that is presented to her. She drops the beads into the box and then knows that she is free to wander around the room for a while. The 'meaning' of the beads from Angela's perspective - 'sitting down with the others to do things' - has been socially constructed, and not arbitrarily imposed.

Motivating

One of the highlights of Jill's week is when she has her hair washed. The bottle of shampoo is the appropriate object for 'hairwashing.' One memorable day, only six weeks after the weekly hairwashing routine had started, Jill picked up the bottle of shampoo and gave it to a member of staff. According to the school staff, some of whom had been working at the school for many years, this was the first time *ever* that Jill had made an intentional communication. Jill was then 18 years old. Her teacher once said to me 'Why does everyone have objects of reference for toilet? My grand-daughter is 2 and doesn't have an established toileting care routine, but she would rather talk about the Tellytubbies!'

Richard used to go to see the music teacher once a week - an activity he dislikes - in a room that he dislikes. He used to become quite agitated when presented with the so-called object of reference, and this of course discouraged him from trying to communicate with anyone in a positive way. The activity - and the object of reference - were discontinued in favour of a regular session on the resonance board, which Richard used to help move into place.

Frequent

Abdul loves going to watch rugby matches, but, because of various constraints, he can only go twice a year. His special hat is kept out of sight until a day or so before he goes to a match. However, he also enjoys going to the video shop to hire a video, and this object - the plastic ticket given out by the shop - is kept out on permanent display at home as a frequent and realistic item of choice.

Sarah, who is deafblind, was discovered to have a passion for cheese! The local supermarket helped to provide a list of cheeses (a very long list, too) that were sold there, and nearly every day, Sarah used to put on her small backpack and go with her intervenor to the supermarket, where they would buy an untried make of cheese. They are still working their way through the A to Z of cheeses!

Reading Objects (2): Storytelling

Secondly, when considering the use of objects within everyday situations with someone who does not communicate with intent, storytelling activities provide many opportunities in which children can be encouraged to hold and manipulate objects. Chris Fuller's series of BagBooks, for example, provide a package of objects to be used with a particular story and are excellent examples of object use in literacy activities. The objects are not functional in the utilitarian sense - using a shopping bag because you are going to go shopping - but are concrete illustrations of objects used in various stories. In this way, children can be encouraged to handle objects for a different, but equally important, purpose.

Similarly, in the following interactive version of 'The Three Little Pigs' that I have recently been using with colleagues (and children!), each child has a small box of objects, and is encouraged by a member of staff to hold and manipulate each object at the appropriate time. Each box contains some bits of straw; several sticks tied together (for the roof of sticks); some pieces of brick for the house of brick; a piece of fake fur for the wolf, and a sprayer for a member of staff to use with the group as the 'wolf' falls in the cooking pot. Various lines can be recorded on to Big Mack switches or step-by-step communicators to encourage the interactivity. We are also consulting the school physiotherapist and speech and language therapist so we can include appropriate movement and communication aims for each child during the activity, and so develop storytelling as an interdisciplinary exercise. The narrator speaks the introductory line and the rest of the story follows in call and response style, each line of which (apart from the final section) is twelve beats. The strong repetitive rhythms, combined with the call and response, encourage children to become more engaged in the activity.

The Three Little Pigs

1. Once upon a time there were three little pigs. The first pig built a house of straw. The wolf came to the door and he said:

Little pig, let me in, little pig, let me in! (mime knocking on the door)
No, no, no, by the hair on my chinny chin chin! (signing 'no, no, no')
Little pig, let me in, little pig, let me in! (mime knocking on the door)
No, no, no, by the hair on my chinny chin chin! (signing 'no, no, no')
Then I'll huff, and I'll puff, and I'll blow your house down (holding then releasing the straw)
And he huffed (gasp); and he puffed (gasp); and he blew the house down!

(everyone falls sideways to activate their switch that says 'crash!')

2. The second pig built a house of sticks. The wolf came to the door and he said:

Little pig, let me in, little pig, let me in! (mime knocking on the door)
No, no, no, by the hair on my chinny chin chin! (signing 'no, no, no')
Little pig, let me in, little pig, let me in! (mime knocking on the door)
No, no, no, by the hair on my chinny chin chin! (signing 'no, no, no')
Then I'll huff, and I'll puff, and I'll blow your house down (holding then releasing the sticks)
And he huffed (gasp); and he puffed (gasp); and he blew the house down!

3. The third pig built a house of bricks. The wolf came to the door and he said:

Little pig, let me in, little pig, let me in! (mime knocking on the door)
No, no, no, by the hair on my chinny chin chin! (signing 'no, no, no')
Little pig, let me in, little pig, let me in! (mime knocking on the door)
No, no, no, by the hair on my chinny chin chin! (signing 'no, no, no')
Then I'll huff, and I'll puff, and I'll blow your house down (holding, and keeping, the brick)
And he huffed (gasp); and he puffed (gasp);
And he huffed (gasp); and he puffed (gasp);

And he couldn't blow the house down!

Thank goodness! (recorded on all the switches)

4. So the wolf and the pig said to each other:

Now I'll climb down the chimney

I 'll catch him in the pot

I'll catch that little piggy

The water's very hot!

Oooohhh!! (Spray everyone with a plant sprayer;)

And the wolf ran away and was never seen again!

Conclusion

Jonathon Bolt (Bolt, 1999) has rightly pointed out that objects of reference and literacy are two sides of the same coin. Using objects in functional settings as well as in storytelling activities has considerable potential, because they help to develop the range of object use and help objects to become 'readable' to their users. This is preferable to introducing an arbitrary set of objects for National Curriculum subjects which may meet the needs of the school, but has no relevance to the complex needs of someone who does not communicate with intent. The last words should go again to Alberto Manguel: "It is the reader who must attribute meaning to a system of signs, and then decipher it. We read to understand, or to begin to understand" (Manguel, 1996, p 7).

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THE O.O.R'S LAMENT

*I'm an Object Of Reference
I'm as lonely as can be
I sit for hours and hours on end
And no one looks at me*

*I long for human contact
To ask for that's not much
But it seems so very clear to me
I will get no human touch*

*The minutes tick on by
And still I sit and wait
For hours and days I'm in this box
Wondering what will be my fate*

*Will I always be forgotten?
Am I of no earthly use?
If so what am I doing here
When I could be on the loose?*

*I could be quite important
I could be of some use
I could be helping all of you
So why make me a recluse?*

*Please don't just ignore me
Please don't write me off
I really only want to help you
And not to piss you off*

*Can we maybe have a fresh start
Can we maybe think again
Can I please be used and used and used
So I wo'nt need this sad lament*

Beryl Brookman
Somerset Social Services
Learning Disability Team

FICTION FOR ADULTS WITH PROFOUND LEARNING DISABILITIES

Fiction, literary works invented by the imagination, tales that are probably totally irrelevant to their everyday lives - what a refreshing concept for people with profound and multiple learning disabilities.

Unfortunately there is a dearth of material for people with these disabilities as they mature, but multi-sensory stories or Tactile Stories as they are more widely known have been shown to provide a suitable means of access to stories for children with PMLD and there is no reason to exclude adults from this same source of access.

Tactile Stories consist of separate pieces of A3 card to which are attached a single material or object which the listener can touch, hear, smell or see as the story unfolds. This sensory input is ordered in two ways. One is to ensure that after one or two 'touching' page cards, for example, a really attention alerting sound or action will sustain the listener's engagement, and the other by introducing whole group attention focus by something dramatic that everyone can receive quickly such as a rattling tin or a wafting card creating 'breeze.'

The objects and materials themselves can be absolutely anything that gives clear sensory information, areas of large bold colours, light reflective papers, sequinned or metallic materials, an infinite variety of textures to feel with face, neck, hands or head, unusual things to feel, anything from boxing gloves to a trolley wheel to a tiara! Many objects have interesting sounds too, which are quite specific, a bicycle pump, a letter box, door knocker, whistle. Some sounds can be designed for the story - gravel in a plastic box (the character walking along the beach) a rustling bag, a stone in a tin.

The list is endless and therefore the possibilities for story content are endless and if one is not targeting language acquisition of everyday useful objects then there is no need to choose them. The strong possibility that the potential listeners will not have come across the objects before can be seen as a bonus. The exception could be a story about their favourite leisure activity such as riding, where the associated objects and materials have interesting multi-sensory aspects anyway, and will evoke pleasant memories.

With each page being separate, they can be offered precisely within the listener's best field of vision, hearing and touching, and time can be given for them to focus their attention and to respond at their own pace and in any way they choose or have at their disposal.

The stories need to be short, seven or eight page cards long and, if the story scripts are in large type on separate A3 cards which can be placed nearby, it leaves the teller free to help the listener to access the pages.

Now the story-line - what makes a good tale - for this is what will engage the storyteller and listener and will be the most important aspect of the activity, lifting it from being interesting sensory cards in a good order, to enfolding and engaging the listener in the atmosphere of a narrative event. What does a good story provide that makes it interesting? I would suggest that it usually has a strong central character or characters, not necessarily human, and that this is an essential element for a story for people with PMLD, as the storyteller has to be able to picture what they are like in order to reflect that image in their voice and the way they tell the tale.

There is a gradual build up of suggestion that something is going to happen, it happens or doesn't, and there are consequences. The subject matter is endless, it might be about crime, love, tales about travelling, tragedy, disaster or humorous events. It is interesting because it transports us from the confines of our own experiences into the experiences of others or comfortably supports what we ourselves have found to be true.

As an example, one could write a crime story about a bank robbery with the most interesting contents: an alarm / black muslin (stocking mask!) heavy tin of money / grill of the Securicor van / security helmet / weapon and smoke smell / police whistles etc. etc. Good clear repetitive phrases, "Don't move!" "Hands up!" - a real thriller!

Humour could be an evening or a week-end at a "Fawlty Towers" type hotel. This idea came from Kristina Fuchs and Tricia Johnson, two members of staff writing very successfully for their own post sixteen client group. Their story included the reception desk bell, large menus and poor service which culminated in the waiter spilling the soup all down the guest who eventually stamps out in disgust!

Travel has many possibilities, attending a wedding in India, an eventful holiday in Australia. Only the means of access needs to be at a suitable developmental level, the content idea can be totally age appropriate. Therefore although the story is short, it needs to be about a very evocative 'happening' to enable the listener to get caught up in the atmosphere of horror, excitement, thrill, charm, humour etc. through the exaggerated pauses, tones and intonation of the storyteller's voice.

The style of writing for the story script is also important in that the sentences and phrases also need to be short so that the listener has very clear auditory information from the voice which is not too long to process. For our crime story it could be 'The bank was very *quiet*. No-one saw the figure slip in. "HANDS UP AND **DON'T MOVE!!**"

The story and its multi-sensory contents, also has to be efficient if it is to sustain frequent use. A storage crate to keep it in, materials and objects glued, sewn or tied on to the page cards so that they are not 'borrowed' for another activity, new objects and materials, all fabric hemmed, anything likely to fray such as cord, secured appropriately and spare batteries, smells etc. always in the crate. The artefacts also

need to be practical. During a recent workshop on tactile stories, one group had the lovely idea of making tiny holes in the fingers of a rubber glove and filling it with water as their character was off to milk the cow. Great fun and a most interesting tactile experience but to arrest the potential disaster to the rest of the story, they would be including a suitable warning about storing the glove very carefully afterwards!

Once made or purchased, it is a most useful resource. It needs no preparation, is stored easily, only takes one person to tell it, nobody has to be moved out of their chair and up to six people can enjoy it at one time. For this very reason it is likely to be used frequently and for the person with PMLD this will give them the opportunity to become familiar with the sound phrases and to associate them with the page cards.

The stories also provide an ideal arena for social interaction and communication. The storyteller in this intimate setting is in a perfect position to respond and reply immediately to any reactions from the listeners and to encourage inter-peer awareness and contact - as suggested by Ouvry

"It is not possible to provide friendship or to make friends for other people but it is possible to create circumstances, give support which will make it easier and more likely that people with PMLD can establish a variety of relationships and fulfil their social, emotional and practical needs." Ouvry (1998)

The storytelling and listening situation is a good 'circumstance' in which to encourage people to practise and use the necessary skills which will help them to sustain interaction within their own social circle.

In conclusion, a multi-sensory tactile story provides an unchanging, structured, interesting activity, often repeated, which can be enjoyed alone with the storyteller or with friends. As the tales become familiar, they are likely to give increased pleasure to the listener as she or he anticipates what is going to happen and communicates this knowledge to someone who will notice and respond.

Chris Fuller
Bag Books

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Tactile Stories for children and the first for teenagers are available from:

Bag Books 60 Walham Grove, London SW6 JQR.

Tel: 02073854021 email: bagbooks @appleonline.net

MAKING THE MOST OF YOUR LIBRARY

Many people have a notion that libraries only lend books. Libraries do a lot more. Even books that they lend have a wide range of formats. Besides books in normal print, there are books in large print, books on tapes, board and cloth books for babies, picture books for under-fives, tactile stories, and for those whose first language is not English. There are books in many other languages. For children there are beautifully illustrated books in dual-text as well. Libraries lend audio and video cassettes, CDs, maps, posters, charts and sometimes toys and pictures as well.

However one aspect of libraries' work that most people tend to forget is that they are centres of information. Libraries have a wide range of periodicals and newspapers, reference books and many have CD Roms and internet which are tremendous source of information both for adults and children. Librarians are willing to show how to use these if you have never used them before. Librarians themselves are a source of information and they are able to answer most of your queries and if they are not, they are able to refer you to someone else who is. Libraries also provide services like photocopying, receiving and sending faxes and use of word processors. Some have minicom facilities. The music section in libraries have special facilities to listen to music.

In this article I wish to tell all those who work with children with profound and multiple learning difficulties how to make the most of their libraries. Children's libraries in Britain are well advanced and I would say that a librarian's professional skills are used at best in this section of the service. Children's librarians help their readers with a varied and large number of queries. Children's libraries are throbbing with activities. There are daily story telling sessions for children on class visits and under-fives who come with their childminders; in summer there is a wide range of activities, such as reading competitions, leisure activities like badge and card making and origami; entertainments like puppet and magic shows; workshops based on many different themes and parties to celebrate festivals like Christmas, Diwali, Eid and Chinese New Year.

Libraries exhibit art work done by your children. I know that although most of these activities are geared for children with no learning difficulties, libraries are for ALL children. If as a parent of a child with PMLD you need a special service, demand it. As a council tax payer your child has the same right to use the library as much as any other. If you are not a good story teller see what the librarian can do for you. She could lend you stories on audio and video tapes. You could ask if the librarian could visit the group your child might be attending to tell a story.

Once again do NOT forget that librarians can give you all sorts of information - addresses of statutory and voluntary bodies providing advice, support, counselling and any other relevant service your child may need, information about relevant activities for your child in and around your area, and they may be able to tell you where to acquire any resources you may want to purchase for your child's development and comfort . And also remember there are many information leaflets translated into other languages which some of you may find useful.

Every book has a reader and there is something for everyone in your library.

Bhadra Patel, Retired Librarian

(Librarian in Charge - Wandsworth's Multicultural Library & Information Service 1977-1999)

The teaching of English and literacy to secondary aged pupils with profound and multiple learning difficulties

Contextual Issues to the Development of a Curriculum for Pupils with Profound, Multiple Learning Difficulties (PMLD)

In 1996 the School Curriculum and Assessment Council (SCAA) published a booklet on planning the curriculum for pupils with profound and multiple learning difficulties (PMLD). The booklet recommended that teachers draw upon additional curriculum material in order to provide an appropriate context for pupils with PMLD to engage in subjects of the National Curriculum. Teachers were advised to select material from all aspects of the Programmes of Study from the National Curriculum, in recognition that the attainments of pupils with PMLD can often be at levels significantly below their chronological age. The booklet also referred to the 1995 NFER *Small Steps of Progress in the National Curriculum* and provided advice as to how the progress of pupils, who have these acute types of special educational need (SEN) may be demonstrated. Although the advice contained within these publications continues to be helpful, in so much as it provides a contextual basis for the teaching of National Curriculum subjects to pupils with PMLD, there is little tangible advice to illustrate to teachers how pupils with PMLD should be engaged in the National Curriculum in a way that will enable them to make progress.

In a similar way, much of the current advice about Target Setting, within the National Curriculum, is not immediately relevant or realistic to the education of pupils with PMLD. There is little current advice available from Governmental sources about how Target Setting can lead to formative teaching in schools which cater for pupils with PMLD, and even less guidance about how Target Setting might lead to effective learning on the part of PMLD pupils. The accredited advice that is available currently (eg Equals 1998: *Baseline Assessment*) has limited practical application for use in the classroom and appears to rely upon the notions that all learning is developmental by nature and that individual curriculum components (located at pre-level 1 levels) have a relative value, against which the effectiveness of teaching and learning can be judged on a national scale. The notion that the achievements of one pupil with PMLD can be judged as having a greater value than the achievements of another pupil with PMLD, without any reference to the types of disabilities being experienced by the pupils concerned, is not viewed as being entirely helpful nor desirable by the authors of this article.

There are encouraging signs, however, that the education of pupils with acute types of SEN may soon benefit from authoritative advice. The Qualifications and Curriculum Authority (QCA) have indicated that they intend to publish curriculum guidelines for use with pupils with SEN and have established a project group to research and develop advice upon which the QCA will base their proposed publication '*Curriculum Guidelines for Pupils Attaining Significantly Below Age-related Expectations*'. It is important that these proposed guidelines pay proper regard to the learning styles of pupils with PMLD and to the context of their personal disabilities. There is a risk, because of the complexity of educating pupils with PMLD, that the proposed guidelines will only give a token recognition of the need for the emerging curriculum model to be responsive to the circumstances of

profound disability. The guidelines need to be more than a set of ideas about how to access pupils with PMLD, in a passive way, to a curriculum that is often alien in its content and organisation if they are to have value in the classroom.

There is solace to be gained from the current hiatus between research into the education of pupils with acute SEN and the publication of the proposed guidelines. This solace comes from the QCA's invitation to teachers of pupils with Severe Learning Difficulties (SLD) to become actively engaged in the curriculum guidelines project. There is a real opportunity for the content and organisation of these proposed curriculum guidelines to be partly shaped by those who know, understand and empathise with pupils with PMLD and teachers need to respond to the invitation extended to them by the QCA. If nothing else serves to prompt teachers to contribute to this current QCA project, then the prospect of curriculum guidelines which may have the potential to be used for reporting pupil performance, informing procedures for benchmarking SLD/PMLD school effectiveness and for determining performance related pay for teachers of pupils with SLD/PMLD, ought to serve as a suitable prompt.

The Teaching of English and Literacy to Pupils with PMLD

In recent times much attention has been focussed upon the teaching of English and in particular upon the teaching of literacy. Considerable, welcome attention has been directed towards how the literacy hour can be made relevant to pupils with SLD (Bainbridge 1999) but there remains precious little advice about how the teaching of English, particularly literacy, can be made meaningful for pupils with PMLD.

There have been some courageous authors who have sought to rein in the rush towards implementing an 'adapted' literacy hour for use with pupils with PMLD, in an attempt to provide a more child centred approach to the teaching of literacy to pupils with acute SEN. For instance, Locke (1999) has sought to emphasise that some of the approaches, advocated in the organisation of the literacy hour in SLD schools, may be counter to what we understand about the development of language itself. Locke argues that there needs to be more value placed upon a distributive style for the teaching of language and literacy, as opposed to the current reliance upon a focus of one literacy session per day.

Nind and Hewett (1998) recognise that many attempts to teach language skills to pupils with PMLD result in poorly developed and erratic functional communication skills. The reason for this may be that in the rush to enable a child's entitlement to literacy, teachers may not fully appreciate that language and communication needs to be reciprocal at all levels and as such requires the active participation of the pupil. Coupe-O'Kane and Smith (1994) also highlight the need for reciprocal communication strategies and recognise that staff working with pupils with acute SEN often over compensate for a pupil's disabilities and direct the total learning experience, at the expense of ensuring that the pupil with PMLD is actively participating in the experience. It may be the case that when a pupil with PMLD is unable to communicate in a reciprocal, socially appropriate manner, the difficulty in communicating is viewed as an integral part of a pupil's innate disability. When a pupil is thus mistakenly labelled as 'non-communicating' it is more likely that their involvement in English and literacy lessons will be of a passive nature, with only a cursory sensory based learning experience bolted on to the class activity, organised to provide some relevance for pupils with PMLD.

Insufficient attention is often directed towards identifying a pupil's potential to communicate and for developing their functional understanding of basic communications which are, of course, the building blocks of language and literacy. Bruner (1975) advises us that the foundations for language and communication are generally learned during the first two years of life. Pupils with PMLD benefit from continued attention being directed towards helping them develop a basic form of reciprocal communication, in a manner that is in empathy with their residual sensory abilities and behavioural characteristics. Teachers need to learn to use the pupil's personal learning style, or behavioural characteristics, to shape their teaching style accordingly.

The ideal methodologies for engaging pupils with PMLD in the teaching of English and literacy, are those which utilise what we know about a pupil's preferred way of interacting in order to engage them in learning experiences which are meaningful, motivational and reciprocal. The relationship between teachers and pupils with PMLD is very different to that which is experienced between teachers and pupils with other types of SEN, and particularly between teachers and pupils have no significant SEN. The teacher who works with pupils with PMLD has a definite second role to undertake in addition to their teacher role, that of being a care giver. The role of care giver brings with it an intimate knowledge of the whole child, a luxury that is rarely available in other teaching environments, and teachers of pupils with PMLD ought to use this intimate knowledge of their pupils to shape their teaching methodology accordingly.

The Baginton-in-the-Fields English Scheme

The Baginton-in-the-Fields English Scheme (the English Scheme) is a comprehensive curriculum model for teaching of English to secondary aged pupils with SLD and PMLD, developed by a multidisciplinary team over the past four years. The English Scheme revolves around a framework of Schemes of Work (SoW) which provide teacher guidelines for engaging pupils in all aspects of the English curriculum. Each SoW benefits from a corresponding sensory curriculum outline which gives ideas as to how individual pupils with PMLD can be engaged in the learning experiences, according to their preferred learning style.

An extensive set of English resources has been developed, in support of the English Scheme, which has at its core a set of reading books. Each book has been carefully illustrated by a professional artist, to present a short pictorial story that introduces a character or family from the fictitious Baginton-in-the-Fields. Each book deals with personal, social and health related issues that are relevant to pupils of secondary age and that can be used to teach reading skills at three distinct levels. In support of pupils with PMLD, each book has a sensory book equivalent in which textures and shapes, that are associated with the subject matter, can be used with pupils in an interactive way. Interactive stories have also been written in which movement, sound and textures can be incorporated into a story line that equates with the subject matter of the corresponding reading book but at a level and in a style that matches the idiosyncrasies of individual pupils with PMLD.

The use of language within the English Scheme is carefully controlled and has been developed under the direction of the school's senior speech and language therapist. A core vocabulary provides the basis for the use of language and each SoW introduces new words in a functional manner. Extensive resources are used to provide a real life context to the language that is being used. Each SoW, for instance, has a character bag in which the clothes and real life props of the character being introduced

are available for pupils to dress up in and use to establish concrete reference points for future teaching. To extend this opportunity for experiential learning to pupils with PMLD, each SoW also has a sensory box containing scents, textures and sounds which are representative of the character in question and are used to rehearse reciprocal communications without the need to segregate these pupils from the main theme of any given literacy lesson.

The English Scheme has been designed so that literate pupils may progress in their reading skills towards their optimum level of literacy but the scheme also allows for considerable lateral learning, to accommodate and celebrate the learning of less able pupils. All pupils progress through the same sets of English SoW, at the same rate, regardless of their personal ability level. The English Scheme's innate emphases upon differentiation by both task and outcome, together with the use of teaching styles which are empathetic to individual pupils with PMLD, all work to ensure that learning experiences within English and literacy lessons are meaningful and functional to all pupils.

A joy of the English Scheme is that pupils with PMLD are actively engaged in English and literacy lessons in a manner that matches their idiosyncratic learning styles. The scope for lateral learning within the scheme, and the equal values that are placed upon each pupil's achievements within the English Scheme, allows pupils with PMLD to progress at the same rate as more academic pupils through the framework of the scheme, thus helping to ensure that the attainments of all pupils enjoy equal status. Anticipated outcomes, in terms of pupil performance within the English Scheme, are realistic and there are no tokenistic expectations that pupils with PMLD will become literate as a consequence of their active participation within the English Scheme. However, there is a definite expectation that pupils with PMLD will make solid progress within their reciprocal communication skills, as a consequence of their active participation in English and literacy lessons, in a manner that is both age appropriate and inclusive.

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HOMEWORK PACKS/TOY LIBRARY

We are two Nursery Nurses working at Glenvale School, West Bromwich. The school caters for students from 2 -19 years, all with SLD or PMLD. The school is a Sandwell LEA school, close to the centre of West Bromwich in the West Midlands. The pupils are drawn from all over the borough of Sandwell.

Three and a half years ago, we joined the English Curriculum Working Party, as a result it was suggested that we launch a homework system primarily based on language activities.

We began by sending home a letter to parents to see how much interest there would be in such a scheme. We were surprised at the positive response and decided to set up a pilot scheme. We selected 12 students from Early Years and Middle School. We liaised with the teachers involved with these students and discussed their abilities and targets on which they were working.

We set about making some English/Language packs. Each pack included guidelines on how to use the packs, an evaluation sheet for parents' comments and an explanation sheet, explaining the aims and contents of the pack. We decided to send the packs home on a Friday, to be used over the weekend and we asked them to be returned on the following Monday. All the returned packs were checked for missing pieces and damage, and repairs were carried out if required, ready for the packs to be sent out again. The evaluation sheets were also assessed.

Due to the success of the packs it was decided to introduce Maths to the homework scheme and to offer the packs to Upper School and Post 16 students.

In 1995 the school, through the LEA, put in a successful bid as part of the Single Regeneration Budget. This money enabled us to expand the English and Maths homework scheme and introduce a toy library. The money was also used to buy in cover so that we were able to be released to work on the project.

To help maintain the quality of the packs, we asked parents for a voluntary contribution of £2 per term. We also introduced an up to date resource file, which gives an outline of each pack available.

Even though we found a lot of the toys were suitable for the students with PMLD, we realised some students, due to their physical and sensory impairments, could not access the homework packs. We decided to make sensory packs (e.g. massage, tacpacs, smelling games, tactile books and feely mats) all of which included explanatory sheets to give parents guidelines for their use.

After three and a half years, the project is still ongoing. We now have an extensive range of packs covering all abilities and ages at our disposal. Half of the school are taking advantage of this scheme. The response from parents has been very favourable. We aim to continue to develop the homework scheme and toy library.

For any further information contact:

Helen Lamb or Sue Walters, Glenvale School, Jervoise Street, West Bromwich, W. Midlands. Tel: 0121 525 5873

Literacy Hour

It was with some degree of trepidation, mild amusement and I have to admit a certain amount of scepticism that we embarked on the training for the Literacy Hour. We came to terms with reality when the message filtered through that from now on the Medium Term Plans would include a separate and very different format for the Literacy Hour. Then came the suggested book list, which included the phrase 'can be adapted!'. To cut a long story short, Freda, (my right arm/mentor/guardian angel! stress councillor), commonly referred to as my assistant, and myself spent many hours pouring over children's books - trying to find simple text; objects to match pictures; sounds; smells; and other clues to make the story make sense to our group of six youngsters with multiple impairments.

Our first story 'Whatever Next' proved quite successful, as like baby bear, we searched kitchens and cupboards to find everything we needed. After a few weeks we were beginning to see flickers of recognition in the children's responses.

We gradually began to tighten up the structure of the hour, incorporating existing good practice into a new era of language and literacy. The first fifteen minutes consists of a big book with individual children having access to a simplified version. (using colour computer pictures which link to the objects, which are then laminated and bound). Some of the books adapted this year have included 'Peace at Last', 'The Bear Hunt' and 'The Train Ride'.

The literacy hour is carried out four days of the week and the first two sections remain the same. After the story the word level section includes a 'What's your name' song, supported by a photograph and a flash card, and a song using the initial sound of the child's name. For those children with visual impairments, tactile letters and sand trays are used. The third section of the hour changes each day, incorporating a sound location activity, hand function class, and aspects of conductive education. The plenary offers opportunities to refer back to the story, and to praise good work. Repositioning within the hour is vital especially if pupils are standing, so stand-by chairs need to be available.

Freda and I have witnessed unbelievable progress, both in the level of concentration of our pupils, and also their ability to anticipate the next activity in a familiar sequence. I am currently hoping that Freda's enthusiasm and resourcefulness will be maintained as we embark on the adaptation of the Numeracy Hour!

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Students with Profound and Multiple Learning Difficulties Enjoy the Literacy Hour

In the early Spring of 1998, I attended a literacy meeting organised by a leading publishing house. Their guest speaker was a teacher who had been working on the Literacy Project and had piloted much of the Literacy Framework. The speaker's enthusiasm was contagious, it wasn't so much the framework, or the clock, or the teaching strategies that had roused her passions, rather it was the knowledge that possibly for the first time in their lives, her mainstream pupils were enjoying books and through that enjoyment the children were learning to communicate.

Questions from the floor revealed concerns. No, not all children were developing at the same pace and Yes, it was difficult to stick to the timings. She didn't have all the answers, but she was certain in the knowledge that through the power of literature the literacy hour had enormous potential. I wanted the students that I worked with to have access to the same level of enjoyment that is to be had from a good book and the warmth and companionship of sharing a book with someone special.

At that time I was privileged to be working with Key Stage 1 students experiencing severe, and profound and multiple learning difficulties. Although I was relatively new to teaching, I quickly realised that if the text was pitched at the right level and the children were able to interact with the story then their response was no different from that of any other child. It was exciting to watch faces light up with anticipation of what might come next, to see students with very limited mobility exert tremendous effort to press a switch to say that they would like more of a story and to watch a child whose body was rarely still, grow calm, concentrating on the steady rhythm of a repetitive text.

Nevertheless, the Literacy Strategy was an untried mainstream initiative, could it work with our children? It seemed to me that deriving pleasure from books is universal and if the cornerstone of the Literacy Strategy was enjoyment of books then we were on an equal footing with mainstream schools.

Our school was blessed with a Head Teacher who had both vision and trust, a vision that included extremely high expectations for all the students in her care and trust in her staff that they were all working to the best of their ability for the benefit of the pupils. Quite rightly the staff, a very experienced team, approached the strategy with caution, but together we arrived at the definition that, in our school, to be literate meant to be able to communicate.

Our starting point in April, 1998, was to assess what was currently happening with literacy. A teacher questionnaire asked questions on timetabling, frequency of lessons, length of lessons, ability grouping, and the role of support staff. Teachers were asked to use what were then only in a draft form, DfEE 'P' scales to award a level for each of the three strands of reading, writing and speaking and listening. Analysis showed that there was a natural break down into three ability levels ranging from pupils with only very limited sensory awareness right through to pupils who were beginner readers.

This was a broad range of literacy skills, which up to now had been addressed through a mixture of small group and one to one teaching. Nevertheless, it was something that would have to be reconciled if all of our students were to be offered equal access to the Literacy Strategy. We had an advantage in as much that the strategy itself held many parallels with the way lessons were delivered in this special school. Teaching to suit a limited attention span meant that our students were used to experiencing several short activities with a recall session at the end. It was therefore decided to take our objectives from the Reception Year targets, or preceding skills, and to conduct the

shared reading and plenary sessions as whole class activities. Individual needs as detailed on I.E.P.s would be addressed during middle sections of the hour.

A literacy audit highlighted many gaps in our resources. Resources that were age appropriate at the top end of the school for the Key Stage 3 students were and still are, a particular cause for concern. Publishers offer very little that is appropriate for this age group with a simple enough text and pictures that are sufficiently clear. However, we trawled the best that was available by inviting a different publishers representative in to school for a twilight demonstration once a week for about two months.

Working as a team the staff, including teachers and support staff, used twilight sessions to sort our stock of big books into batches that were suitable for each key stage. We were also able to judge whether we had a broad enough range of fiction and non-fiction texts.

Although it could be argued that the pace of using a different text every week was too brisk for students experiencing profound and multiple learning difficulties, it was nevertheless felt to be important to enhance a student's experience through exposure to as wide a variety of texts as possible and also to maintain interest for staff as well as students. We cleared a big space for literacy resources and bought lots of brightly coloured storage boxes with the intention of equipping each of our big books with objects of reference that would facilitate access for all of our students.

For students experiencing profound and multiple learning difficulties, as well as gaining experience and enjoyment from the texts our aim was to enhance their communication. Whilst it could be argued that we were teaching pre-reading skills which were outside the scope of the Literacy Strategy, we believed that the basics of communication must precede all other skills, therefore communication is the forerunner of reading and writing skills. Indeed this could well be a level that many of our students may never exceed, but that is not to say that these skills are any less valued.

Consequently, our plans included using characters and objects from each book to produce tactile pictures, Makaton symbols, three dimensional objects, photographs, items to reproduce sounds and smells all linked to the big book. With these objects in place we could develop meaningful activities such as object recognition, object to object and object to picture matching and so on. We could develop sensory awareness through the use of paint or sand writing. We could encourage the use of switches and the ability to control the immediate environment. Choice making could be enhanced and through the use of CDs, audio recordings, and with the benefit of information technology such as scanners and digital cameras the possibilities became enormous. Use of a large hand puppet with a moveable mouth meant that we could really encourage tongue movement and lip closure. Some activities linked beautifully to the text, but where there was a need but no obvious link we were not afraid to design stand alone activities.

In fact the possibilities became too enormous and it was quickly realised that to equip books in advance in this way was almost impossible. Without specific objectives it was difficult to say what would be required. Greater experience of the Literacy Hour showed that it was better to equip each text as it was used with particular pupils or groups of pupils in mind. Over time use of the same texts by different classes has resulted in a gradual accumulation of resources to suit a variety of purposes.

Equipping 'This is the Bear' produced differentiated activities and resources that met several individual needs within the shared and guided sessions of a mixed class of students experiencing severe as well as profound and multiple learning difficulties. Some pupils were able to read the text. Other pupils were encouraged to identify pictures through verbalisation, switches or eye pointing. A brightly coloured textured baby bear pasted onto a dark background encouraged sensory awareness and tracking. Pupils were encouraged to make the appropriate lip closure to produce a bbbb sound and good use of Derbyshire Language resources facilitated the purposeful activity of the children deciding whether to place a teddy bear on or under the bed to encourage the understanding of positional language, not to mention making the children go into fits of laughing at the silly notion

that the bear might sleep under the bed.

Experience of failure and success of putting literacy resources together also lead to the possibility of collaborating with our local lending library to produce similar literacy packs thus enabling youngsters with learning difficulties in the community to access texts via the public loan system. There was also an opportunity to work on a similar project with the Local Education Authority librarian for loan packs to be made available within the school system.

Early on during the introduction of the Literacy Strategy it was realised that two elements were of vital importance. The first was the accurate targeting and monitoring of individual needs and the second was the means of delivering them. The school had always implemented Individual Educational Plans, however, early experience of working with the Literacy Strategy revealed that some of the objectives previously specified on the I.E.P.s had been too broad and were not specific enough to show either the up-ward or in some cases the lateral progression made by our students. In order to be able to set achievable weekly targets that could be monitored and assessed to produce the next crop of targets we needed to refine our planning. We redesigned all of our planning and recording systems to encompass the model of plan, do and review, so that assessments fed directly back into our planning. Eventually this was simplified by representing the system as a simple flow-chart. It also had the additional benefit of providing consistency of approach throughout the school. In addition we were able to produce school wide quantifiable data, which hopefully would provide comparisons for future years, and indicate areas of Literacy that we were focusing upon, and whether there were any areas that we needed to strengthen. Infant base-lining together with Easter base-lining for the whole school provided tangible evidence of progression as well as making end of year reports much easier to write.

However, all of this depended upon the second element that we had discovered that was of vital importance and that was the means of delivery. Because our students were unable to work independently the third segment of each hour required that every group had to have supervision and teaching input. During this session, students broke down into three or more ability groups. A member of staff taught each group, with the class teacher working with a different group each day. This highlighted the importance of all staff being included in the Literacy Training. It also necessitated knowledge of teaching objectives in advance and participation in the assessment process.

To make sure that these assessments were fed back into future planning, routines were amended so that on one night each week, each department would hold a planning meeting whilst other staff attended to end of the day bus duty.

The head teacher and senior management team of the school had created an ethos where staff could work in a non-judgemental atmosphere. Staff had been allowed time to get to grips with the strategy in their own way and come to their own realisation of the potential of harnessing the power of literature. As Literacy Co-ordinator, I was fortunate in having opportunities to observe this in practice. Monitoring sessions revealed how previously hesitant teachers had taken possession of the strategy and were really beginning to communicate their enthusiasm for literature to their pupils. It was at this point that learning was really beginning to take place, it was also a point that reinforced just how much we had to learn from one another as a staff.

Sue Atkins
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Although Sue no longer works at the school which is Oakwood School, Druids Walk, Walsall Wood, Walsall, W. Midlands - Tel:-01534 452040 The headteacher is Kay Mills.

LITERACY AND DRAMA

I'm hooked on drama. It all started last Summer Term when I did part of 'Odyssey Now' with my class of pupils with PMLD and a senior class of pupils with SLD. It was so successful that I did some more. Last term it was 'A Christmas Carol' and that was great too, but what should I do after Christmas - especially important as we were having an Ofsted! I looked at 'Romeo and Juliet' but it didn't suit the particular group of pupils I teach, so there was nothing for it but to write my own. My husband happened to be watching a programme about tornadoes and then it hit me, why not do 'The Wizard of Oz'. So the Christmas holidays saw me reading the original book and working out how I could put it across - well there was nothing to watch on TV!

The following is my adaptation which I have developed to suit the needs of the pupils I teach, 5 pupils with PMLD, ranging in age from 6 to 12 years and all wheelchair users, and a class of 8 pupils with SLD aged 12/13 years who help my children to participate. I can't say it's all been successful yet, we've only got to Scene 3 so far! Anyway I hope it gives readers some ideas and I'd certainly be pleased to receive ideas for other adaptations as they might help me in the Easter holiday when I'm planning drama for next term.

The Wizard of Oz

Scene 1: The Cyclone

- Storyline:** Dorothy is on her farm in Kansas, when a cyclone suddenly comes and she is taken up by the wind, along with her house.
- Props:** Large parachute
Straw hat
- Music:** Mendelssohn - Symphony No. 3
- Game:** *Caught in the cyclone*
Pupils sit in wheelchairs with their helper, one at a time on the middle of the parachute.
Music plays. Pupils chant "The wind is coming, the wind is coming".
Pupils hold the edge of the parachute and shake the parachute up and down..
Then they say "It's a cyclone" and move around in a circle enfolding the central pupil in the middle of the cyclone.
- Aims:** Excitement and anticipation of the wind.
Experiencing separation from the group.

Scene 2: Arriving in the land of the Munchkins

- Storyline:** Dorothy and the house land on top of the Witch of the East, killing her. Only the witch's magic silver shoes are visible from under the house.

- Props: Small parachute/small blanket
Silver shoes
- Game: *Who will it be?*
Pupils sit in a circle, while 2 hold up the small parachute and move around the circle chanting "The house is landing, the house is landing.....on you".
The parachute is brought down on a pupil and then lifted up, while silver shoes are thrown on the floor.
The one on whom it landed points at themselves and says "It landed on me".
Everyone else points at the person who it landed on and says "It was you and you've lost your shoes".
- Aims: Declarative pointing
Self awareness

Scene 3: Going to the Emerald City

- Storyline: Dorothy wants to get back to Kansas and is told that the Great Oz could help her. She is instructed to follow the Yellow Brick Road to get to the Emerald City where The Great Oz lives. On the way she meets the Scarecrow, who wants some brains, the Tinman, who wants a heart and the Lion, who wants to be brave.
- Props: Yellow ribbon
Bean bags
- Game: *Follow my leader/Simon Says*
The pupils line up behind one another and follow the leader as they go around the floor picking up yellow bean bags. When they've all been picked up, the pupils form a circle and play a game of "Dorothy says". Dorothy wears the straw hat to indicate she's the leader and then does simple actions for all to copy. Pupils take it in turns to be Dorothy.
- Aims: Awareness of others
Imitation of others

Scene 4: Arrival at the Emerald City

- Storyline: The friends arrive at the gates of the Emerald City. The Guardian of the gates greets them and tells them to wear green glasses. He asks them if they really want to see Oz, The Terrible. They have to wait some time and then they go to see Oz, one by one. He appears in different forms to each of the friends. Oz says he will help them if they go and kill the Wicked Witch of the West.
- Props: Green games bands to wear on heads or over shoulders.
Green cloth
Pictures of large head (no body), beautiful winged lady, 5 eyed, armed, legged beast, fire.
- Music: Trumpet Voluntary - Purcell

- Game:** *Who's brave enough?*
 One pupil plays the guardian of the gates. He asks each pupil in turn "What do you want?"
 Pupils reply "I want to see Oz."
 The guardian then gives each person a green band to wear and then lets them in. When all pupils have entered into the city, they wait in line to see Oz.
 The servant shouts out "Who is brave enough to see Oz? If you are, you must go alone."
 Pupils take it in turns to go in. As they enter they see a green cloth. Behind the cloth, a pupil chooses a picture to show, from the choice of 4. Will the picture be scary or not?
 Pupils are told to kill the Wicked Witch of the West
- Aims:** Receiving a token
 Anticipation
 Looking towards an object

Scene 5: In the castle of The Wicked Witch of the West

- Storyline:** The witch has used the magic powers of the golden cap to get the winged monkeys to capture the lion and Dorothy. Dorothy is set to work in the castle, while the lion is locked up. The witch tries to get Dorothy's silver shoes off her. When she tricks Dorothy and manages to get one of the shoes, Dorothy is so cross she throws a bucket of water over her. The water is like poison to the witch and she melts away and disappears completely. Dorothy and the Lion escape and after a few more adventures are reunited with the Tinman and The Scarecrow.
- Props:** Silver shoes
 Water spray
 Witch's hat
- Game:** *Get the shoes*
 Pupils stand in a circle or move around the room passing the shoes from person to person.
 The witch follows the shoes around the room and tries to intercept and capture one of the shoes.
 When she gets a shoe, Dorothy goes to her and sprays her with water. When the witch gets wet, she is out.
 Repeat the game with someone else as the witch.
- Aims:** Tracking an object
 Attention skills

Scene 6: Back at the Emerald City

- Storyline:** Now that the witch is dead the friends return to The Emerald City to see Oz and to get him to fulfil his promises. When they see Oz again they find he is not a wizard after all, but a bald old man who lost his way years ago when ballooning. However he says he will still help them to get what they wanted.
- Props:** 3 Boxes with a stuffed hessian head, a heart shaped cushion and a bottle of green potion.

- Game: *Pass the Parcel*
 Pupils sit in a circle and a box/bag containing one of the above is passed around the circle.
 When the music stops, the pupil holding the box, opens it and sees what is inside.
 Pupils can ask who wants a heart etc.
- Aims: Turn taking
 Anticipation
 Showing objects

Scene 7: Going Home

- Storyline: The Scarecrow, who now has brains, the Tinman who now has a heart and the Lion who is now brave, go with Dorothy to find the Good Witch Glinda. On the way they have to pass through the fighting trees and the land of the Hammerheads. Having successfully come through these difficulties they meet the Good Witch who tells Dorothy that the silver shoes which she is wearing are all she needs to get back to Kansas. All she need do is to bang the heels together 3 times.
- Props: Foam javelin
 Foam cushion/wedge
 Bells
 Small parachute
- Game: *Getting free from the trees*
 Several pupils hold hands together and pretend to be the trees.
 One by one the other pupils try to get across the room without being caught by the trees.
 If they are caught they must shout for help to the Tinman who comes with a foam javelin to cut them free.
- Game: *Hammerheads*
 One pupil is a hammerhead and holds a foam cushion in front of their body.
 They try to stop pupils passing by.
 Pupils who cannot get past, go back and ring some bells for help.
 When the bell is rung they can then get past.
- Game: *Tap the shoes*
 One pupil is the Good Witch Glinda.
 Pupils take it in turn to go up to her and ask her what to do.
 She tells them to tap the shoes together 3 times.
 They then pass under the parachute and arrive back in Kansas.
 As pupils arrive back they sit in a circle and sing a happy song.
- Aims: Awareness of others
 Anticipation
 Awareness of sounds

Hilary Leigh,
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 Park, K. Dickens for all: Inclusive approaches to literature and communication with people with severe and profound learning disabilities, *British Journal of Special Education*

Reading for All – Ideas for stories and Reading for children and young adults with severe and profound disabilities

Reading for All is a collaborative piece of work that aims to promote access to literacy in all its forms for children and young adults with profound intellectual and multiple disabilities.

It is a resource pack full of ideas on how you might share stories with children and young adults and of how they might become actors in the drama of story telling, poetry and theatre.

Contributions were sought from schools, colleges and universities, parents, authors, drama workers and other interested communities of interest. The ideas generated have been structured into a simple format to make it accessible to the widest possible audience. The principal aim was to inspire readers to then having a go themselves. There are examples of how to make a tactile story book; a complete bedroom environment with multi-sensory panels, quilts and fabrics ('Changing Rooms' are interested in filming this one!); bag books; adaptations of classics; imaginative uses of computers and associated technology; and examples of life story books that parents and teachers have made with individual children and young people.

The Packpack was produced by MENCAP, The Royal Schools for the Deaf, Manchester, The Royal National Institute for the Blind, Widgit Software Limited and the University of Birmingham. It was part funded by the National Literacy Trust as part of the work undertaken to celebrate the National Year of Reading. The Year ran from September 1998 to August 1999. The activities of the year have now been extended and renamed the 'Read On' initiative. The Pilgrim Trust and Walker Books Ltd granted additional funding.

Some criticism has been levelled at the definition of literacy contained in the Pack, some feeling that it is too broad. The definition used includes basic communication and social interaction as fundamental aspects of communicating with the world around you and of reading events and social interactions. It is argued that having stories read to you is as much a reading act as is reading it for yourself. Those who contributed to the Pack wish to promote the view that:

- Books do not have to be conventionally read to be enjoyed
- Information and stories do not have to be conventionally understood in order to learn from them
- Stories do not have to be conventionally written down to convey meaning

The authors see this definition as being more inclusive and less restrictive than one that narrowly defines literacy as the ability to decode standard orthography or text.

The pack is not a reading scheme but is intended to offer a broad range of ideas to stimulate thinking around access to the world of stories.

The review in the Times Educational Supplement of 29th October 1999 described the pack as,

'... thoughtful, inspiring and highly relevant to those working with children and young adults with profound and multiple learning disabilities and their families.'
(TES, 20.10.1999)

The Pack is now being used as the basis for a CD-ROM to bring some of the stories to life on the computer screen. MENCAP is seeking funding to do this so that the process of sharing stories can be demonstrated visually with helpful hints about how to engage the child or young person more fully in the reading act.

MENCAP hopes to organise some Workshops with partners to demonstrate some of the brilliant ideas that have come forward. There were a number of Workshops run during the development of the material for the Pack and these will now be extended to include real hands on experiences of making and trying out props and story lines.

MENCAP would like to thank all contributors to the Pack, whether or not your ideas made it in to the final version. There were some heated debates and with a tight time-scale before the National Year of Reading ended, some tough decisions were made, mostly to do with the amount of time and space left to produce the Pack.

Particular thanks must also go to Carol Ouvry and Penny Lacey for their work in drafting and redrafting sections of the Pack and to the Royal Schools for the Deaf in Manchester for their photographs, contributions from staff and the patience of the children in receiving so many visitors to see the story telling sessions in action.

This pack is available from MENCAP Bookshop, MENCAP Public Liaison Unit, 1123 Golden Lane, LONDON, EC1Y 0RT. (£20 for schools and colleges, £10 for MENCAP members and £5 for parents.)

For more information about the Pack or for an update on the development of the Workshops for parents and teachers, please contact:

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Extract from the Introduction of the Report of the Disability Rights Task Force on Civil Rights for Disabled People

"the most beautiful and enriching trait of human life is diversity - a diversity that can never be used to justify inequality. Repressing diversity will impoverish the human race. We must facilitate and strengthen diversity in order to reach a more equitable world for us all. For equality to exist, we must avoid standards that define what a normal human life should be or the normal way of achieving success and happiness. The only normal quality that can exist among human beings is life itself."

Dr. Oscar Arias, President, Costa Rica

This quotation was sent in by John Lawton

New developments in Symbols Software and their implications for reading and writing achievements

Since the mid 1980s pictorial symbols have been used in the UK to support communication for children with severe learning difficulties. The advent of computer software which makes the manipulation and reproduction of symbols comparatively easy has helped the use of symbols to spread through schools and into adult communities. The initial use as support for communication has been extended into print based materials and literacy.

As an alternative or augmentation to text symbols can provide some people with access to emergent literacy experiences and to participate in literacy activities (1997, Detheridge and Detheridge). Children who are not able to access text are writing stories, creating newspapers and, more recently, writing poetry. In adult communities non-text users use symbols for accessing information, writing diaries and life stories as well as supporting daily living. In both communities access to printed information in the form of timetables, rotas, instruction or help sheets is helping personal autonomy and independence. It is beyond the scope of this article to illustrate these, but examples are available in magazines, publications and on the Internet.

This growth has caused a number of pressures on the symbol vocabularies available and on the software tools used to manipulate them. In the mid 1980s the vocabularies stood at around 800 words, comprising mainly nouns and verbs with some essential prepositions and adjectives. In 1993, the program Writing with Symbols, provided the first 'symbol processor' where users could write directly and easily in symbols. At this time there was only one vocabulary available electronically, which started at around 1500 words. The software was designed mainly for teachers and carers to create symbol materials for non-text readers, but the use of overlay keyboards and on-screen grids soon brought writing within reach of many users. Immediately there was pressure to increase the vocabularies and by 1996 the vocabulary had risen to 3600. In addition other symbol publishers had electronic versions of their vocabularies. The range of task being undertaken was extending. Users wanted flexibility of display and in 1998 a new version of the software, Writing with Symbols 2000, was published which performed in much the same way as any other commercial word processor, with the addition of a full range of sound and graphic facilities for creating supported writing.

Many questions have arisen as a consequence of these developments. What are the realistic and practical limitations of graphic symbols to represent complex ideas? Clearly not every word in the English language can be represented graphically. Transparent symbols which are easily understood require very little teaching and learning. As the concepts, and therefore the representations, become more opaque, more teaching and

learning becomes necessary. How do we determine which users are able to understand which types of symbol?

Within the UK there are three pictorial symbol sets in common usage: Rebus, Makaton and PCS. These have developed from the same roots and so there are many common structures which underpin their schema. Many of the variations are stylistic rather than fundamental, in much the same way that different fonts are used in printed text. Some users are able to transfer between one type of image and another. However, there are many professionals who believe that symbol users will be confused by this variety and that there should be a single symbol set.

There is little research in this field, and we have little solid evidence on which to base these discussions. It is possible that in much the same way that most of us are able to distinguish between the great variety of symbols for public services, such as the symbols for toilet, so people with learning disabilities may also acquire capability to generalise.

The rate of change in symbol use is increasing very fast. The currently published vocabularies combine to represent some 9000 different concepts. Users are becoming less worried about 'pure' symbol sets, and we are seeing professionals drawing on the full range of images available in order to select the most appropriate for each client or situation. As well as using symbols available in formal published sets, the software allows users to add their own personal images. Digitised photographs of people and places are complimenting the general vocabularies. Scanned images from books clip art and other sources are adding to the variety of image used. This further challenges the initial assumptions on symbol comprehension and standardisation.

Another important aspect of symbol design is its democratisation. The early vocabularies were developed by professionals who became the publishers. As the use of symbols increases it is both feasible and appropriate that some users are able to collaborate in choosing and even specifying the symbols they require. In the absence of research on design, user involvement can help to ensure that the developments do not spiral out of hand.

Some of the use of alternative images to bring local and relevant images into the writing is quite appropriate. However there are other occasions where inappropriate images are used, or otherwise, where a crucial concept is not represented graphically because no appropriate symbol currently exists. In either case the resulting print is incomprehensible. Instances of this are reducing as the vocabularies grow and experience grows, but it is something we need to take care about.

In an attempt to address some of these problems, new mechanisms have been added whereby users can build symbols for themselves. It is hoped that in this way the symbols created will adhere more closely to the underlying conventions, and extend in some measure towards a linguistic base. For example the use of graphic qualifiers has been extended. A back arrow either above or below a verb has long represented past

tense. The new tools allow images to be joined together so that one graphic qualifies' another. For example the time image to create dinner time or tea time, or the shop element to add to an item or category to create shoe shop, dress shop etc. Users are no longer restricted to the shops imagined by the publisher, but can develop their own variations in a logical structure.

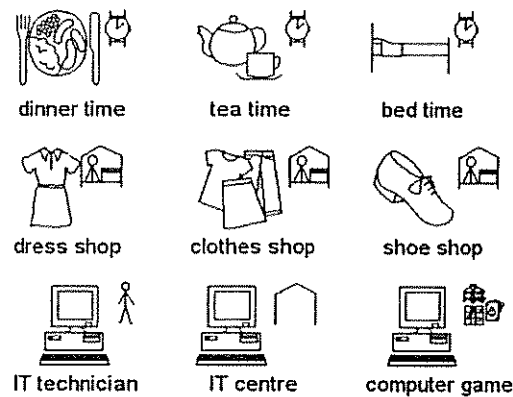


Fig 1 - Examples of graphic qualifiers used to extend symbol vocabularies.

These large vocabularies are significant in one sense. They reflect the range of communication purposes demanded. However, unless there are mechanisms for non-text users to write, and manipulate them for themselves the entire initiative will at best be patronising. There are three ways in which a non-text user may write, each of them useful in their own way. The most direct is through an amanuensis. In this situation the author dictates, or otherwise indicates the content. The crucial issue is one of authenticity. Alternatively, the user can select symbols from a set provided by a teacher or carer. The advantage in this approach is that the author also constructs the writing. The disadvantage is that there is inevitably a limit to the vocabulary available at any time. Overlay keyboards normally present a small vocabulary which the user assembles from short sentences or phrases. The physical dimensions of the board limit the selection. An on-screen grid provides multiple 'layers' of content that the user selects. The user can navigate through layers. The vocabulary available at any time is limited by the physical space available on the screen alongside the document, and by the cognitive limit for understanding the information structure.

The Chailey Communication System, devised for use by non-speech children at Chailey Heritage School, is a vocabulary structure whereby the user can reach any word in the system through a very small number of 'moves'. This requires the user to understand the categorisation system of the words. Recently this was made available through on-screen grids so that users could access vocabulary in the same way for writing as they used for speech. However, in practice, Valerie Moffatt, from Chailey, has realised that the sequence of words used in direct communication is not necessarily the same for writing. It is likely that different approaches will be needed as users want access to more extensive vocabulary selection sets at any one time.

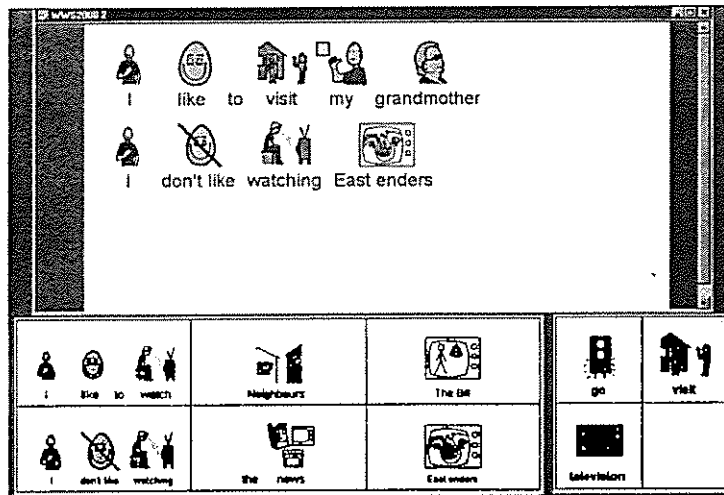


Fig. 2 Phrases provided on the left grid, can be selected to go into the document. Selecting a cell on the right grid changes theselection set on the left. In this example there are phrases concerning television programmes, places to go to and people to visit.

It is evident that since such structures are not yet available, users are not able to independently access vocabulary in these ways as text writers, and probably not to the limit of their comprehension. However, there are examples from schools, colleges, day centres showing that there are people able to read and write using symbols who previously did not have access to either capability. Gill Lloyd, a teacher working with young adults, reports that some of her students who are unable to read text are becoming quite sophisticated readers of symbols. Whereas initially they read at the 'key-word' level of symbol/text support, they now demand a graphic to support every word. They can independently extract meaning from print, and some are able to write creatively, wither on their own or with help. Students working with Clare Martin, at George Hastwell School in Cumbria use symbols in all aspects of their learning. From discussion about the Kosovo crisis to exploring Shakespeare.

Access to literacy through symbols clearly will not create skills beyond an individual's capability, but the anecdotal evidence does suggest that the new tools and the enlarged vocabularies which are now available increases access, and can increase achievement for many children and adults.

Tina Detheridge May 1999
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Writing with Symbols 2000 published by Widget Software Ltd.
Rebus Symbol Collection published by Widget Software Ltd.
Makaton Symbols published by the Makaton Vocabulary Development Project
PCS symbols - Picture Communication Symbols published by Mayer-Johnson Co

news ... news ...news....

OAKLANDS COLLEGE WINS BEACON AWARD

Congratulations must go to Oaklands College of Further Education in Hertfordshire on winning the 'Professor John Tomlinson Award for Inclusive Learning for Adults with Profound and Multiple Learning Difficulties' as part of the Beacon Awards administered by the Association of Colleges.

The Award is sponsored by MENCAP, NIACE (The National Organisation for Adult Learning, based in Leicester) and FEDA (The Further Education Development Agency).

The cash Award recognises the excellent provision made for adult students with profound and multiple disabilities at the College, which is to be seen as a beacon of excellence in the standards of provision made for other colleges of further education to aspire to achieve for themselves.

John Lawton, MENCAP's National Education Officer for Adult Services said that,

"The standard of provision made for students with profound and multiple disabilities was excellent. The attention to individual need, communication mode and preferred learning styles was outstanding. This proves what colleges of further education can achieve, even within the constraints of current funding arrangements.

At a time when the Learning and Skills Bill is passing through into legislation, it is vital that we have examples of how mainstream further education providers can provide excellent provision given the commitment and resources to do so. This standard of practice must become the norm and not the exception in further, adult and community education if the Government's vision of lifelong learning opportunities for all is to become a reality."

For more information about the Beacon Awards, contact:

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report back

MENCAP NATIONAL FOCUS GROUP ON PIMD

Seminar 4 Lifelong Learning Opportunities for People with Profound Intellectual and Multiple Disabilities

The Seminar was opened by David Congdon, MENCAP Director of Public Affairs. He outlined the major strategic review which will take place over the next five years with an emphasis on self determination and advocacy, but highlighted the danger of exclusion of people with PIMD. The emphasis on lifelong learning is one way in which this challenge can be met.

'Reading for All - Ideas for stories and reading for children and young adults with severe and profound learning disabilities' an introduction to the pack - Penny Lacey

In this session Penny introduced the pack recently published by MENCAP and described how it all started with an initial questionnaire sent out widely to find out who was doing what in terms of using literature with children and young adults with PIMD. This produced a great deal of material about the use of stories and other forms of literature, many of which have been used in the pack to illustrate the information and ideas contained in the various sections.

Penny made the points that:

- Books do not have to be conventionally read to be enjoyed.
- Information and stories do not have to be conventionally understood in order to learn from them.
- Stories do not have to be conventionally written down to convey meaning.

Penny then asked What is Literacy for children and young people with PIMD? and concluded that it covered the following:

- Access to communication
- Communication systems
- Objects of Reference
- Technology to support systems
- Improving interactions
- Access to books and literature
- Co-creativity

She commented that parents may need help to get started on using stories and books, and this could be support from schools - giving homework to 'look at books' or may be a link with a technology centre to support the use of literature. However, as well as practical aspects, the magic, fun and enjoyment of reading is very important.

Penny then showed some 'pages' of a tactile book called "Desmond" (produced by Bag Books) and talked about the importance of pace, repetition, and the involvement of siblings. She then showed a video of a three young children (one of whom had PIMD) listening to an adult reading 'Desmond' to them with evident enjoyment. Members of the seminar group were so involved that they wanted to watch to the end!

Penny talked about how to go about adapting books. Those which are good for this purpose include:

- a strong storyline and characters
- sudden surprises or build up to tension and then release
- opportunities for contrasting moods, sounds or smells or things to look at
- gentle rhythmical words
- possibilities for joining in
- spaces for dramatic pauses
- lots of repetition

She showed one or two books which would be particularly suitable for adapting for young people, including *Greek Myths for Young Children* by Marcia Williams (Walker Paperbacks) and *The Hound of the Baskervilles* by Arthur Conan Doyle.

Learning for Life - Chris Jones

Chris Jones is a full time lecturer based at Walsall College of Continuing Education.

She outlined the general aims for her role as tutor: to develop

- awareness of self within the environment, using sensory stimulation
- preverbal communication skills
- peer group interaction
- receptive and expressive language

She is currently engaged in a joint project with a speech and language therapist to put together a broad curriculum for the development of communication skills for people with profound learning disabilities.

Chris works with people who are not able to access the college, and she described how she was able to work with 25 people each week through outreach work in a day centre. Although there are funding problems for equipment such as communication technology, she is setting up a book resource and hoping to expand this to include videos and story tapes.

Her teaching is non-schedule 2 i.e. students are not working towards a qualification. Her post is part funded by the local council and the FEFC.

A number of questions arose from her presentation:

Could direct payment be used to buy 'educational' services rather than social care?

Should there be some form of educational input on a regular basis throughout life for people who will not get a job?

How can meaningful activities be balanced with educational courses?

How can education continue in everyday settings? Can the model of care include the learning process?

Is it appropriate for outreach education to take place in students' homes?

"Learning to Succeed: A New Framework for Post 16 Learning"

What implications are there for access to lifelong learning opportunities in the Government's White Paper? - John Lawton

John gave a brief description of the reorganization of post 16 funding which gave rise to the Further Education Funding Council (FEFC) from 1993. Local sector colleges became independent and autonomous, and college provision was linked to the needs of industry and the world of work.

The *Tomlinson Report* reported increasing instances of exclusion from FE and found that students with disabilities were less likely to have lifelong learning, with poor provision, no curriculum or progression routes, and lack of inclusion. Some groups of students who challenge the system (those excluded from school, with mental health difficulties, and PIMD) were missing.

The emphasis on courses with an accredited outcome made people unsure how to fit in these groups. Students were required to demonstrate the capacity to succeed in higher levels of course before entry, giving rise to Entry Level awards.

The Government is now proposing to reshape the FEFC into Learning and Skills Councils in 48 regional areas under a National Learning and Skills Council. The local Learning and Skills Councils will replace colleges, TECs, FEFC, Career Services. LEAs will have a legal duty to fund the *care* of students, rather than the *education*.

Other developments include:

Separate inspection frameworks for up to 18s and 18+ .

The new Code of Practice is not expected until 2001.

The QCA Project - *School Curriculum for Pupils with Severe and Profound Learning Difficulties* will be in schools by September 2000. There will be a 2 year trial and it will then become statutory.

MENCAP has sent a detailed response to the Government White Paper raising a number of issues and concerns which need to be addressed.

Discussion

A wide ranging discussion followed, with the following key issues being identified:

Access to Learning

Funding issues

Inequalities across the country

Information and support for appropriate provision - regular reviews, personal plans and essential lifestyle planning

Training opportunities for staff in Colleges (e.g. different definitions of special needs)

Need for advocacy

Broad view of education needed

Involving people in their own planning decisions

Legal rights for adults with PIMD

Exclusion from education on health grounds (medical/ behavioural)

Essential to base provision around needs.

All education is on a 'trial and error' basis because we don't know how children with PIMD learn.

Issues in Transition

Joint working and communication between education, social services, health and employment.

Transition plans are too early.

Need for transition links and preparation for the move to adult education.

Lack of information for parents about the options and the need for a key person for support within agencies.

Lack of valuing of achievements, leading to poor provision and lack of expectation of learning.

Inadequate provision - part time leading to increased burden of care in the family.

Training for parents.

Lack of funding for research into PIMD issues. Estimated population of people with PIMD in England and Wales is 30,000.

Social and educational exclusion - lifelong learning is not a right.

Curriculum

Must take into account preferences and styles of communication

Should be multidisciplinary

Should take account of how children and adults learn.

Conclusion

David Congdon concluded the day by commenting that there is a need to articulate a better case for the educational basis of lifelong learning to compensate for the opportunities for life which most people have through work, social life, leisure etc.

BRITISH INSTITUTE OF LEARNING DISABILITIES

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**Enhancing Quality of Life:
a project to develop transitional
programmes for people with
profound and complex learning difficulties**



Newsletter 1: January 2000

Introduction

Welcome to the new millennium and to the first newsletter from members of the Enhancing Quality of Life project team. This newsletter will tell you about the work of the project so far and:

- the identification of a small number of case study sites;
- the selection of a part time research and development worker.

We invite you to make contact with us if you wish to find out more about either of these opportunities to become more closely involved with the project.

As you may recall, the Enhancing Quality of Life project is concerned with the development of transitional programmes for people with profound and complex learning difficulties. The National Lottery Charities Board has provided funding for this collaborative venture over three years. The project manager is Liz Maudslay of SKILL (the National Bureau for Students with Disabilities) and Lesley Dee of the University of Cambridge School of Education is project director. During the first phase of the project, the research has been undertaken by Lani Florian and Richard Byers, based at the University of Cambridge School of Education. Administrative support for the project is provided by the SKILL office in London and by Peggy Nunn, who will provide your first point of contact with the project, in Cambridge.

Members of the project team have been at work since September 1999 and have also met with the steering group which has been set up in order to guide the project's work. The steering group has a huge amount of expertise and has already made a number of significant contributions to the work of the project. The membership of the steering group is:

- Philippa Russell, Council for Disabled Children (Chair);
- Barry Carpenter, Sunfield School;
- Sally Faraday, FEDA;
- Matthew Griffiths, FEFC;
- Claire Lazarus, SEN Co-ordinator for the Eastern Region;
- John Ladle, Acting Up;
- Robina Mallett, Home Farm Trust;
- Barbara McIntosh, King's College, University of London;
- Marian Roiser, Oxfordshire Social Services and Education;
- Denise Wallace, Oaklands College.

A survey of current provision

In the early stages of the project, we have been conducting a survey of patterns of provision for people with profound and complex learning difficulties in England and Wales. Before Christmas, we set ourselves the task of sending questionnaires to all schools working with pupils with profound and multiple learning difficulties beyond the age of fourteen, whether

local authority funded or in the voluntary and independent sectors. We have already received a large number of returns and we are logging the resulting data.

We are now sending out similar questionnaires to specialist and sector colleges. Our intention is to survey any courses or programmes which make defined and time-limited educational provision for students with profound and multiple learning difficulties post-school – especially where this provision is funded by the FEFC. We have therefore sent questionnaires to providers such as ‘extended education centres’ and joint-funded residential centres.

Our questionnaires have asked for:

- general information about schools and colleges and whether any provision relevant to our survey is made;
- specific information about any provision made for pupils and students with profound and complex learning difficulties in various age groups from Key Stage 4 into adulthood;
- information about links between schools and colleges and between educational provision and other services;
- information about sources of funding for students post-sixteen;
- information about provision, placement and options for people with profound and complex learning difficulties after full time education.

Our questionnaires have all included a working definition of profound and complex learning difficulties. Our definition, which we developed as a result of reviewing the literature and in discussion with the project steering group, states that:

People with profound and complex learning difficulties share two characteristics:

- a profound cognitive impairment or learning difficulty and
- a complex aggregation of difficulties in more than one area of their lives.

These people make extreme demands upon services, often because of additional combinations of physical disabilities; sensory impairments; medical complexities; and/or social or behavioural difficulties. Staff will almost certainly experience exceptional difficulties in establishing reliable and consistent methods of communicating with them. Staff may find it difficult to view people with profound and complex learning difficulties as adults as they grow older because of their extensive and ongoing support needs.

We are already aware that the phrase ‘profound and complex learning difficulties’ appears to mean a number of different things to different practitioners working in different contexts. For this reason, we are keen to establish some common and consistent understandings about the shared characteristics and needs of this group of students as far as our project is concerned.

It is too early to report any findings from our survey here, but we will provide some details in our next newsletter, due in early summer 2000. We will also be submitting more extensive articles about patterns of provision to journals for publication.

Reviewing the literature

As a second part of the first phase of this project, we are undertaking a review of the relevant literature. The purposes of this literature review are to:

- secure the project within a theoretical context;

- discover examples of innovative practice;
- provide a sense of the ways in which practice might develop.

We anticipate that this literature review will be written up as one of the outcomes of the project and that we will also produce an annotated bibliography in order to facilitate access to key texts in this area of work for practitioners and future researchers. Although we expect the literature search to inform us about a range of issues – such as approaches to staff development, policy making processes and research methods – which are important to the success of this project, the literature search is currently focused on seven substantive areas of enquiry.

- Who are people with profound and complex learning difficulties?
- How should judgements about quality of life for people with profound and complex learning difficulties be made?
- What do we mean by transition and when does it take place?
- What are the priorities in developing an appropriate transitional curriculum for people with profound and complex learning difficulties?
- What are the most effective approaches to teaching and learning for people with profound and complex learning difficulties?
- How important are collaborative, inter-agency approaches to working with people with profound and complex learning difficulties?
- What is the role of advocacy in developing transitional programmes for people with profound and complex learning difficulties?

If you consider that your practice might help us to explore any of these areas, please do get in touch with us, remembering that we are particularly interested in joint funded, collaborative and imaginative projects.

We are very grateful to all of you who have already sent us brochures or prospectuses about your own provision or letters or information sheets describing your work. The questionnaires have also asked you to send us details of interesting provision that you know about. We are logging all this information and using it to help us identify examples of unusual and innovative practice. Please continue to send us this sort of material and to alert us to practice which we ought, in your view, to know about. This may be particularly relevant in the light of the next major task faced by the project team, which entails identifying case study examples of provision.

Selecting case study provision

Members of the project team will be working in close collaboration with a small number of case study providers from April 2000 until August 2001 in order to explore:

- curriculum development and delivery including:
 - definitions of progress and achievement;
 - innovative teaching and learning processes and strategies;
 - the organisation of time and resources;
 - the management of the learning environment;
 - effective record keeping and assessment practices;
- inter-agency collaboration including:
 - the negotiation of clear criteria for allocating roles and responsibilities;
 - efficient approaches to high quality communication and information sharing;

- establishing partnerships in practice between professionals, families, enablers and people with profound and complex learning difficulties themselves;
- promoting and working with a range of forms of advocacy, including:
 - individual self-advocates;
 - group advocacy;
 - supported advocacy, with family members, peers, enablers, key workers, professionals, citizens and named persons acting as advocates;
 - advocacy through voluntary bodies and lobby groups;
- analysing opportunities for and obstacles to inclusion in the local environment including:
 - existing provision;
 - practical access to facilities;
 - the skills and approaches of professionals, enablers and members of the community.

We are currently developing selection criteria and processes which will enable us to identify a short list of case study sites. We will then identify a final set of case study providers in summer 2000.

Our work with these case study providers will enable us to produce a range of materials to support innovative practice and staff development. These materials will probably include: text, video, audio-tape, ICT resources, OHPs, exemplar planning and recording formats, practical teaching materials and examples of best practice. We will only be able to work in depth with the selected case study sites in order to develop these materials. However, if you feel that these developments might be particularly relevant to your work, you may wish to become part of the programme of consultation in the later phases of the project.

The project also needs to appoint a further part-time research and development officer who will be working directly with the case study providers and contributing to the development of project materials. This post might suit a practitioner who can negotiate a part-time secondment; a research worker; or someone who maintains a portfolio of part-time and independent roles in practice, staff development, research or consultancy. The job will be advertised in the press and further details will be posted on the SKILL and University of Cambridge School of Education websites. Alternatively, if you wish to receive a full set of job specifications please contact:

Mrs. Peggy Nunn,
University of Cambridge School of Education,
Shaftesbury Road,
Cambridge. CB2 2BX.

Email: pln20@hermes.ac.uk

You may also wish to make contact with us in order to offer comments or information in respect of any of the issues raised in this newsletter. We will maintain information on our website at:

www.skill.org.uk

and produce a further newsletter in early summer. In the meantime, please accept our thanks for your support, enthusiasm and continuing interest in this project – it is gratifying to be involved in work which seems to be viewed so positively.

Members of the Enhancing Quality of Life project team
January 2000

FUTURE FOCUS The Use of Multisensory Environments

The theme for the next issue of PMLD-Link is multi-sensory environments. This term has been widely used to describe a whole range of environments - some located in separate rooms (or cupboards!) and some assembled in parts of the classroom. Just as their size and location varies, so does their name. For example, they might be white rooms or dark rooms, colour rooms, water rooms, interactive environments, sensory suites or studios. They might also be referred to as Snoezlens. Perhaps the best description of them is that they are designated spaces for the *targeted* use of sensory input.

Pagliano (1998) in a recent book suggests that they are

"a dedicated space or room where stimulation can be controlled, manipulated, intensified, reduced, presented in isolation, combination, packaged for passive or active interaction, and temporally matched to fit the perceived motivation, interests, leisure, relaxation, therapeutic and/or educational needs of the user."
(p 11)

Richard Byers (1998/9) further describes a whole range of different purposes for these environments including:

- curricular work in science, history, geography and English
- assessment
- development of sensory processes
- communication
- cause and effect
- choice and problem solving
- self-awareness and control
- leisure and relaxation

Clearly the environments are important for working both with individuals, and groups, whether children or adults.

We are currently engaged in a project for BECTA, exploring good practice in the use of technology within multisensory environments and developing case study material that can be used by BECTA to provide illustrations that will be available on the National Grid for Learning. This project has confirmed the many different ways in which teachers in a whole range of settings are using these environments.

Despite their widespread use, there is little available research evidence to draw on. It is therefore essential for teachers to evaluate their own practice, to reflect on how they utilise the environments, how they have had to adapt their ways of working, and how successful it is for both individuals and groups of pupils. We urge readers to contribute to the next edition and share with others their developing practice.

The use of MSBs are not without controversy (Orr 1993, Porter and Wrench 1998). Many have argued that a good environment is naturally multisensory. Indeed the use of these environments begs the question "*what can I do in a multisensory environment that I cannot*

do elsewhere ?" This raises the question of the need to evaluate their use not just from the point of how user behaviour develops but also how staff behaviour changes. Additionally others have argued against a focus on technology but the need to concentrate on social interaction. These and the following issues may be ones that readers would like to address in their articles.

- How can we ensure that behaviour and developments of the pupil/client in a MSB links to other work?
- How do we ensure that staff feel competent and well trained in the use *and application* of the technology?
- How can we develop good whole school or organisation practice in the use of multisensory environments and who should be responsible for monitoring this?
- How can we best express aims for people with PMLD with challenging behaviour who use a MSE and how do we measure progress?
- How can we best use MSEs to promote inclusive practices ? How can they be best used as a wider resource?
- How can MSE be best utilised to promote peer-peer interaction?
- How can we work with other professionals to collaborate on the development and use of MSEs?

The focus of these questions suggests that the starting point is to consider the environment and its uses. This is rather misleading - we cannot evaluate a resource or explore the tensions and dilemmas in isolation. We hope that readers will utilise these issues but begin with the needs of those they work with, either as individuals or in groups. If we are to utilise these resources well we need to ensure a good match between individual need and provision. These environments often consume a lot of resources - it is important that we reflect on their use and ensure the continued development of practice.

Jill Porter & Olga Miller

School of Education, The University of Birmingham, Edgbaston, Birmingham B15 2TT

References

- Byers, R. (1998/9) Sensory environments for pupils and students with profound and multiple learning difficulties-innovations in design and practice. *PMLD Link*, 32, 28-31.
- Orr, R. (1993) Life beyond the Room. *Eye Contact* 6, 25-26.
- Pagliano, P. (1998) *Multisensory Environments*. London: Fulton.
- Porter J. & Wrench, K. (1998) Supporting Learning for Pupils with Visual Impairment and Multiple Disabilities: Technology and Other Resources. *Improving Provision for Children with Visual Impairments and Multiple Disabilities*. London: RNIB.

reviews ... *reviews* ... reviews ... *reviews*

Making Dance Special: Developing Dance in the Curriculum with Pupils with Special Educational Needs

Peter, M.
London: David Fulton 1997
ISBN: 1-83546-434

Melanie Peter writes for teachers working with pupils and students with Special Educational Needs about the application and theory of Dance. The book is based on Laban dance and Sherborne Movement.

Chapters include, 'framework', 'body awareness', 'planning' and 'developing quality', plus a very useful and exciting exemplars covering Early Years through to Key Stage 2\3.

She introduces the reader both to the theoretical place of Dance within the curriculum together with some of the 'issues' for those more familiar with the subject.

Dance still remains as part of PE curriculum which has succeeded in disadvantaging teachers who are convinced of the value of Dance, but who lack a theoretical framework to inform both policy and planning.

This book will be of interest to those in education who are interested in enabling pupils with special educational needs to develop creative skills within Physical Education linked to the Creative Arts.

Peter takes the opportunity to link child development through to the National Curriculum in a scholarly way to convince the reader of the value of Dance as Movement, Movement as Body Awareness and Body Awareness linked to interaction and, by implication, communication.

The Chapters 3,4,5, give practical advice on introducing and teaching dance and, pages

66-67 provide a useful overview of what progression may be expected, from 'Pre/Lower Key Stage 1' (emergent) to 'Upper Key Stage 2/3' (communicative).

Melanie Peter has written a scholarly readable text to be used as a source for those searching for a framework and, a practical guide and inspiration for the application of Dance.

(The book would benefit from an update to relate it to the 2000 National Curriculum and some illustrations worthy of the text).

Steve Morris
Head Teacher
Grimsbury Park School, Bristol

Social Role Valorization and The English Experience

Race, David, G.
Whiting & Birch Ltd. 1999 184 pp.
ISBN 1 861770278

This book is definitely not bed time reading. The author, a strong advocate of the Normalisation and SRV theory offers his interpretations backed up with reference sources, and relates these to England. The opening chapter gives a political and historical perspective. However this, by the author's admission, (and throughout the book) is not related to the UK, but only to England - this may limit the potential audience for this book.

The following chapters attempt to explain the evolving theories and their inter-related properties. The author intends this to inform and initiate people to the theories. Mitigating against this is some of the terminology used - in particular the frequent reference to 'wounds'. However

this part of the book would be a valuable resource for someone already versed in the theories and language, but perhaps needing to update themselves, and to witness the extensive body of literature on which this book and the theories are based.

Attempts to relate the theories and ideas to the English way of life include examples at a highly theoretical level with few at a practical level, this could be the result of the author's wish to move the SRV debates away from learning disabilities fields but it makes for very difficult sustained reading. Where practical examples are given some are of an extreme nature, whilst others are open to interpretation as to their validity as examples of the theories.

The author also addresses many of the criticisms levelled at the theories. At times the book tends to read like a personal communication response targeted at academics and critics of the SRV movement, as the author endeavours to demonstrate that the theories are not and should not be on the decline in this country

In trying to identify the potential audience for this book it is probably someone with some existing knowledge of the theories who wishes to interpret the theories into English society. It would be quite a difficult book to dip in and out of, or use as a quick reference book.

However this book, in relating the theories to this country is one of only a handful of published literature to do so. It will certainly contribute and keep alive the debate here - and who knows, may be the start of a wealth of home spun literature which contribute to and move on the theories of SRV and Normalisation, away from the 'over there' theories to the germination of 'our own' theories.

Diana M. Foxwell
Lecturer - UWE
Regional Tutor, University of Birmingham

Using Television and Video to Support Learning: A Handbook for Teachers in Special and Mainstream School.

Edited by Stephen Fawkes, Su Hurrell and Nick Peacey with Julie Coghill, Nicola Grove and Carol Ouvry
London: David Fulton Publishers 1999
112 pp Price £12.00 A4 paperback
ISBN 1-85346-597-6

Television, videos and latterly, computers are so much a part of our lives that we tend to take them for granted. This book provides many useful illustrations of how they may be used to support the learning of children with severe to profound and multiple learning difficulties. Indeed, we must not forget that for many of these children watching TV and videos can be a significant family occasion. Therefore, it is something of a surprise that so little has been written about good practice in their use in the education of these children.

This book addresses this gap in the literature by presenting a collection of case studies and papers by teachers and educationists. It begins with a description of the value of TV and video in special schools as revealed by surveys of the views of teachers and parents as part of the 1993 *Access to Learning* project sponsored by BBC, Channel 4 and others. It contains practical suggestions about planning, viewing and teaching strategies as well as the more suitable programmes. It recognises the difficulties encountered by teachers in using recordings of TV programmes, such as the inconvenient transmission times, the excessive amounts of speech and information densely packed into programmes, and the lack of time and resources for editing programmes to make them more suitable. It emphasises the difficulties that children may have in processing visual information. However, the various authors also show how practical strategies may unlock the huge potential that these programmes offer for all.

The core of the book describes the projects of some special schools and the practical

lessons that the staff have learned from their experiences. The projects involve pupils of different ages and mainly pupils with severe or profound and multiple learning difficulties. Some schools clearly have highly developed resources whereas some are operating with the kinds of facilities found in most schools. As well as providing some interesting examples of meaningful multi-sensory experiences, the writers also communicate eminently practical advice (for example, shoot videos with a camcorder held at the pupils' eye-level rather than an adult's).

The book is somewhat expensive for its size, but not prohibitively so, and the content of some of the sections are rather lightweight. However, it is readable and the authors have an infectious enthusiasm. The future possibilities of TV integrated with Information and Communications Technology are clearly stated. The book deserves to be widely read by the staff of special schools

Rob Ashdown
Head Teacher, St. Luke's School,
Scunthorpe

Learning and Inclusion: The Cleves School Experience

Edited by Alderson, P.
Written by staff and pupils of the Cleves School, Newnham, London.
London: David Fuiton 1999 91pp paperback
ISBN: 1-85346-609-3

This book is relevant to all teachers, parents and governors concerned with the education of children with or without special needs. It is of particular interest to the many schools currently engaged in the inclusion debate with individual LEAs and the DfEE.

The book is extremely easy to read and understands and describes the inclusive principles and daily practices of a 420 place primary school in Newnham. One in ten of these children are described as having

learning disabilities although it is unclear how many have PMLD. The aims of the school set out in Chapter 2 are an excellent point for any school currently reviewing their own.

Within the book, through a series of linked chapters, the staff and pupils illustrate a model of an Inclusive Community School, their aims and the ways through which they achieve them. Parents and governors also contribute their views and many of the principles described have relevance for the teaching and learning needs of pupils with PMLD, wherever their school setting. At Cleves there is a clear commitment to provide access to the curriculum for all children and I was disappointed that the writers did not use more examples of how they managed this for their most disabled pupils. More photos or 'pen pictures' of specific children would have been useful.

Throughout each of the six chapters in the book I felt uplifted by the school's belief in the equal worth of the needs of each child and the quality relationships and teamwork demonstrated between children, parents, governors, staff and the wider community. Useful checklists and pointers for ensuring inclusive practices were contained in each chapter and the Appendices.

Each chapter offered common sense advice on issues related to Inclusion which I think all teachers can relate to. The ability of the school to match their practices to their policies was demonstrated in Appendix 2: Extracts from the 1998 OFSTED Report.

In conclusion, the staff and pupils of Cleves School have written an exciting book which will invite you to dip-in and out of it on a regular basis. Don't read this book assuming approaches and values shared by those working with pupils with PMLD in special schools aren't those shared by staff in mainstream. This is a book which will undoubtedly make us reflect on and question our own practice and consider which educational settings best meet the needs of pupils with PMLD. Although practical in style and approach, this book clearly

examines the issues of ethos which underpin all we do with pupils with PMLD.

E.T. Duffield
Deputy Headteacher, St. George's School,
Peterborough

Pathways to Learning in Rett Syndrome

Lewis, J and Wilson, D.
David Fulton Publishers 1998
Paperback 114 pp Price: £14.99
ISBN 1-85346-533-X

The book is divided into four parts, which are uncomplicated and easy to read, even for the newcomer to Rett Syndrome. It is brilliantly written and is invaluable to any person who is interested in or involved with a girl with Rett Syndrome.

The text covers the most relevant aspects of the syndrome. It provides support and affirmation for those involved with girls with Rett, through discussion of research projects and the author's direct experience. For example, Part 1 examines physical, social, emotional and intellectual factors of girls with Rett in relation to interaction in their daily lives. The many options available in terms of schooling

and general living are also provided.

As the text develops a breakdown of the syndrome is provided giving details of the more specific factors which can affect a girl who has Rett. It also considers the various attitudes which are often encountered by the girls and those around them, helping to provide a holistic picture of what it means to have or be involved with Rett Syndrome.

Although a thin book it is well worth the price, and beneficial to anyone interested in learning about Rett Syndrome. Although I did not agree with all aspects of the book, it is certainly the best I have read up to date. The quotations included enhance the book as they are by respected authorities on the subject. All in all a valuable and interesting read illustrating that:

"The important thing is to focus on what the girls can do, not on what they cannot, or do not, do. It is also important to understand that ability is not only that which can be measured by external achievements - ability is everything that exists within, whether it can be expressed or not." (Lindberg 1991, p.149)

Pat Dolan
Parent

Please Remember

to let us know if you have recently found any books or equipment, been on a course or found a source of information you think might be of interest to other people who work with or care for people with PMLD.

Send us details, and if it was a course perhaps you could send in a brief write up about the contents to put into
report back.

RESOURCES

NEW BOOKS

Disorders of Vision in Children: a guide for teachers and carers written by Richard Bowman, Ruth Bowman and Gordon Dutton. Published by RNIB £19.95 ISBN 1-85878-2139

Adapted Games at Key Stages 1 & 2 written by Bren Pointer. £12.99
Available from Pren Pointer, 78 Doyle Gardens, Willesden, London NW10 3SR

Reading for All: ideas for stories and reading for children and young adults with severe and profound learning disabilities published by Mencap 1999

Implementing the Literacy Hour for Pupils with Learning Difficulties by A. Berger, J. Henderson, and D. Morris. published by David Fulton 1999.

The Fulton Special Education Digest : Selected Resources for Teachers, Parents and Carers. Edited by Ann Worthington. Published by David Fulton ISSN 1-85346-621-2

Taking Turns - Around Recreation and Leisure by Alice Bradley published by BILD 1999
Three booklets to help people with learning disabilities get involved in leisure activities. **To be reviewed in the next issue**

Reviewed in this issue:

Social Role Valorization and The English Experience by David Race. Published by Whiting and Birch 1999 ISBN 1-86177-02708

Making Dance Special - Developing Dance in the Curriculum with Pupils with Special Educational Needs by Melanie Peter. Published by David Fulton Publishers. 1997

Using Television and Video to Support Learning: A Handbook for Teachers in Special and Mainstream Schools edited by Stephen Fawkes, Su Hurrell and Nick Peacey with Julie Coghill, Nicola Grove and Carol Ouvry. Published by David Fulton Publishers 1999

Learning and Inclusion - The Cleves School experience edited by P. Alderson, written by staff and pupils of the Cleves School, Newham, London. Published by David Fulton Publishers 1999

Pathways to Learning in Rett Syndrome written by Jackie Lewis and Debbie Wilson. Published by David Fulton Publishers 1998

New Journal

Race & Disability published by EMERGE (Ethnic Minorities Education and Resource Group for Equality) December 1999 Vol. 1 No. 1 ISSN 1467 6524

COURSES AND CONFERENCES

FEBRUARY

- Date Sherborne Movement - Level 1
unknown Organised by: Sherborne Foundation
Venue: Rolle College, Exmouth, Devon
Further details: Bill Richards
Tel: 01395 270603
- 9th Exploring Sexuality Issues for People with Profound Learning
and Disabilities Parts I, II and III
16th Organised by: Consent
and Venue: Harperbury, Herts
23rd Leaders: Christine Paparestis and Steve Simmons
Contact:f Consent
Tel: 01923 670804
- 10th Stimulating the Senses
and The six senses and how they evolve. Participants will gain
11th experience in creating sensory sessions for service users or
children with learning disabilities.
Organised by: roc
Venue: to be confirmed
Contact: roc
Tel: 01923 663628
- 18th Another Trio of Opportunities
to Dance & Drama (over 18's)
20th Musical Interaction
Towards Numeracy (including PMLD)
Organised by: Special Music Courses
Venue: Great Hucklow, Derbyshire
Further details: Kate Baxter
Tel: 0115 9609528
- 24th Therapy in Schools: Problems, Policies and Good Practice
Organised by: Forum on Learning Disability
Venue: Royal Society of Medicine
Further details: Emma Chaffin
Tel: 0171 290 2988
- 29th Creative Ways of Managing Challenging Behaviour
Workshop to increase knowledge and skills in ways of understanding and
dealing with challenging behaviour in young people with learning
difficulties.
Organised by: Sunfield Professional Development Centre
Venue: Sunfield, Clent
Speaker: Prof. John Pearce
Further details: Jackie Wadlow, Sunfield
Tel: 01562 883183

MARCH

- Date Sherborne Movement - Level 1
unknown Organised by: Sherborne Foundation
Venue: North Hertfordshire
Further details: Alleyne Cliff
Tel: 01462 453094
- 14th Cultural Issues in Sexuality Work with People with Learning Disabilities
Organised by: Consent
Venue: Harperbury, Herts
Leader: Seema Malhotra
Further details: Consent
Tel: 01923 670804/670793

- 16th Music and Communication
 A practical one day course for staff who have little or no experience in music making who wish to use music in day to day work as a means of improving communication for adult clients with a visual and learning disability, particularly those with little or no speech.
 Organised by: RNIB Multiple Disability Services
 Venue: Belper, Derbyshire
 Further details: Simon Labbett, RNIB
 Tel: 01423 880866
- 17th to 19th Diversity and Differentiation - Meeting the Needs of Inclusion
 Conference for teachers, administrators, researchers, support staff and senior managers.. Broadranging topics with choice of workshops, some specifically addressing issues for pupils with PMLD
 Organised by: NASEN
 Venue: Robinson Executive Centre, Cambridge
 Further details: NASEN
 Tel: 01827 311500
 fax: 01827 313005
- 18th Strum as you Sing
 - on the autoharp and chromaharp. Playing success is guaranteed at this one day workshop! All levels welcome.
 Organised by: Special Music Courses
 Venue: Nottingham
 Leader: Tim Gauntley and his team from Toronto
 Further details: Kate Baxter
 Tel: 0115 960 9528
- 20th and 21st Starting MOVE
 Two-day Basic Provider course gives an overview of MOVE philosophy and will allow participants to start using the MOVE curriculum in their own school, centre or at home.
 Organised by; MOVE Europe
 Venue: Scotland
 Further details: Move Europe
 Tel: 01902 323066
- 25th Arts 2000?- Where are the Arts now for children with special needs?
 This conference will address the question in a dynamic and practical way that will take Arts in the Curriculum forward for children with special educational needs.
 Organised by: Sunfield Professional Development Centre
 Venue: Sunfield Professional Development Centre
 Further details: Jackie Wadlow
 Tel: 01562 883183
- 29th Citizen Advocacy: Where Next?
 A one day working conference on quality in citizen advocacy to explore ways in which quality assurance can raise the profile of citizen advocacy, encourage volunteers, and strengthen the role of advocates in partnership with people with learning disabilities.
 Organised by: BILD
 Venue: London Voluntary Resource Centre
 Cost: £31.14
 Further details: Catherine Allsopp
 01562 850251

MAY

10th

Towards a new Sense of Balance

Weighing up difficult decisions in the lives of people with learning difficulties.

Organised by: The Elfrida Society
Venue: National Institute of Social Work, London
Speaker: Prof. Hilary Brown
Further details: The Elfrida Society
Tel: 020 7359 7443

16th

Managers Responsibilities in Sexuality Work

For Managers only

Organised by: Consent
Leader: Mike Hobson
Venue: Harperbury, Herts
Further details: Consent
Tel: 01923 670804/670793

20th

Sherborne Movement - Level 1

Organised by: Sherborne Foundation
Venue: Bristol
Further details: Cyndi Hill
Tel: 0117 937 3647

JUNE

6th

and

7th

Cultural Issues in Sexuality Work with People with Learning Disabilities

Organised by: Consent
Leader: Seema Malhotra
Venue: Harperbury, Herts
Further details: Consent
Tel: 01923 670804/670793

12th

and

13th

Starting MOVE

Two-day Basic Provider course gives an overview of MOVE philosophy and will allow participants to start using the MOVE curriculum in their own school, centre or at home.

Organised by: MOVE Europe
Venue: Scotland
Further details: Move Europe
Tel: 01902 323066

23rd

to

25th

Meeting the Challenge: Challenging Behaviour and the Arts

Challenging Behaviour

Workshops in: Arts Therapies
Communication and interaction
Relaxation and leisure

Organised by: Special Music Courses
Venue: Great Hucklow, Derbyshire
Leader: Dave Hewett
Further details: Kate Baxter
Tel: 0115 960 9528

JULY

4th

Therapy in Schools: Problems, Policies and Good Practice

Organised by: Forum on Learning Disability
Venue: Royal Society of Medicine
Further details: Emma Chaffin
Tel: 0171 290 2988

MAY

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JULY

4th

Therapy in Schools: Problems, Policies and Good Practice

Organised by: Forum on Learning Disability
Venue: Royal Society of Medicine
Further details: Emma Chaffin
Tel: 0171 290 2988

4th **ISEC 2000 : Including the Excluded**
International Special Education Congress 2000
 An opportunity for people involved in special education from around the world to hear about best practice and new ideas, share knowledge and information in more practical ways, visit local facilities.
 Venue: University of Manchester
 Further details: Prof. Peter Mittler
 e-mail: isec@man.ac.uk
 or Congress Secretariat:
 Tel: 01942 608374

5th **Support for Female Carers/Mothers of People with Learning Disabilities**
 for female parents and carers only
 Organised by: Consent
 Leader: Seema Malhotra
 Venue: Harperbury, Herts
 Further Details: Consent
 Tel: 01923 670804/670793

AUGUST

29th **Managers' Responsibilities in Sexuality Work**
 for managers only
 Organised by: Consent
 Leader: Mike Hobson
 Venue: Harperbury, Herts
 Further details: Consent
 Tel: 01923 670804/670793

SEPTEMBER

5th **Cultural Issues in Sexuality Work with People with Learning Disabilities**
 and Organised by: Consent
 6th Leader: Seema Malhotra
 Venue: Harperbury, Herts
 Further details: Consent
 Tel: 01923 670804/670793

6th **Exploring Sexuality Issues for People With Profound Learning Disabilities**
 and Parts I, II and III)
 13th Organised by: Consent
 and Leader: Christine Paparestis
 20th Venue: Harperbury, Herts
 Further details: Consent
 Tel: 01923 670804/670793

12th **Issues of HIV and People with Learning Disabilities**
 Organised by: Consent
 Leader: Bryan Mellan
 Venue: Harperbury, Herts
 Further details: Consent
 Tel: 01923 670804/670793

13th **bild 2000 Conference: Our lives: Past, Present and Future!**
 A conference with people with learning disabilities, carers, staff researchers, parents and families
 Venue: Stakis Hotel, Blackpool
 Further details: Liz Howells
 Tel: 01562 850251

9th Riing O' Rose: Music and Movement in the Early Years
Tuned percussion (melody and simple harmony on xylophones etc.
Movement and dance
Profound and Multiple Learning Disabilities
Organised by: Special Music Courses
Venue: Great Hucklow, Derbyshire
Leaders Janet Sparkes and Penny Lacey
Further details: Kate Baxter
Tel: 0115 960 9528

NOVEMBER

13th Starting MOVE
and Two-day Basic Provider course gives an overview of MOVE philosophy and
14th will allow participants to start using the MOVE curriculum in their own school,
centre or at home.
Organised by: MOVE Europe
Venue: Scotland
Further details: Move Europe
Tel: 01902 323066

LEARNING PACKS

Right to Sight

A training pack comprising a video and supporting booklet for staff working with adults with learning difficulties. It is part of the Access ToEye Care campaign. RNIB £89.00
Available from: RNIB Customer Services tel: 0345-02 31 53 ref. PR11142

LONGER COURSES (with accreditation)

Interdisciplinary work with People with Profound and Multiple Learning Disabilities

A one year distance education course for practitioners and carers of children and adults with profound and multiple learning disabilities. The main focus is upon lifelong learning, communication and effective interdisciplinary collaboration.

Offered at four levels: Post experience certificate (level 1), Advanced Certificate (level 3), Post graduate diploma and Masters (level M)

University of Birmingham School of Education in conjunction with BILD
Further details: Linda Scott, tel: 0121 414 3466

M.Sc/PG Diploma in Learning Disability Studies

1 year full-time or 2 year part-time course.

This course meets the training needs of a variety of professionals involved in delivering services to children or adults with a learning disability, including registered nurses, social workers, doctors, occupational therapists, physiotherapists, speech and language therapists, officers in statutory, voluntary or private establishments, FE tutors, staff of SECs. It provides the opportunity to participate in and contribute to inter-disciplinary learning in a collaborative setting.

Further details: Stuart Cumella or Helen Bradley,
Department of Psychiatry, Queen Elizabeth Psychiatric Hospital, Mindelsohn Way,
Edgbaston, Birmingham B15 2QZ Tel: 0121 627 2853

Profound Learning Disability and Multi Sensory Impairments

Two year distance learning course combined with workshops.

For people who are involved with children and adults who have complex learning needs and sensory impairments.

Offered at three levels: Certificate, Advanced Diploma and Masters.*

University of Manchester Faculty of Education in conjunction with Royal Schools for the Deaf, Manchester.

Further details: 0161 610 0149

e-mail: jtioffice@rsd.manchester.btinternet.com

* Bursaries are available for some Certificate and MSc students. Details available on application to Gill Parkinson, Programme Director, JTI Office, University of Manchester, c/o RSD, Stanley Road, Cheadle Hulme, Cheadle, Cheshire SK8 6RQ

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