

PMILD 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***

The focus for this issues of PMLD-Link is early years and early intervention, and one of these articles combines this topic with an interesting description of support for young children and their parents in Slovenia, written by Prof. Egidija Novljan. Some of the services she describes will, I am sure, trigger new ways of thinking about how we might develop our own services. Other 'home grown' articles give a writer's personal view and a useful look at the SCAA draft proposals for pre-school education.

As usual, we have a number of interesting articles about other topics as well. I just can't wait to get going on a quilt - as I am no longer working directly with people with PMLD it may have to be one of my own!

Some readers may have gone to the Conference on *Issues of Communication* at Manchester in February. Some, like me, may have intended to go, but been prevented by the weather. We arranged with the organisers of the conference that we would disseminate notes on the presentations and workshops, and you will find the first instalment in this issue of PMLD-Link. If any of you attend conferences, courses, or in-house Inset which you found particularly useful or enlightening, do please write in and tell us about it.

The focus for next issue is Information Technology in all its many forms. Tina Detheridge has started the ball rolling in **FUTURE FOCUS** in which she highlights a number of issues which have arisen during her current research. She speaks of the range of purposes for which IT is used, and the problems of assessment specifically for IT. She also identifies two fundamental difficulties in the effective use of IT - *limitations of the technology and limitations of our imaginations*.

Do write in about the ways you have used IT, and whether you have found ways around, or been defeated by the limitations of technology. Let us know about the imaginative ways you approached the use of IT, or perhaps how you would like to develop your work if only you were an IT expert like Tina. Use the next issue to ask for, or pass on, ideas to other readers.

As always, articles on absolutely any topic are welcomed, and we are very grateful to all who have found the time to write articles. I am sure there are more of you out there in the 'real' world who are just longing to tell others about your experiences - successes, failures, tragedies and comedies! Do write, and send your articles in by the middle of June for the Summer Issue of PMLD-Link.

Carol Ouvry

WORKING WITH PRE-SCHOOL CHILDREN WITH PMLD AND THEIR FAMILIES: A PERSONAL VIEW

I began working with pre-school multiply disabled children about four years ago, after training in multi-sensory impairment at Birmingham University. I already had several years experience of working with pre-school hearing impaired children and their families, but in spite of this I found that working with families with a multiply disabled child was altogether more challenging and demanding and presented me with a steep learning curve. I had not been used to planning for younger children with such complex needs and wide ranging developmental levels. Nor was I used to needing to work so closely with physiotherapists and speech and language therapists, and to sharing information with them.

I was very aware that many different people were making demands on the families' time and resources. The numbers of specialist appointments at different hospital departments and clinics seemed overwhelming. Then there were people like myself, asking to visit at home. I was struck by the enormous juggling act that parents are required to perform between appointments, home, work, family life and the needs of other children, as well as catering for the needs of the disabled child. All these things were happening at a time when parents were most likely to be feeling very vulnerable with a very young multi-needs child.

When asked to consider the value of pre-school support to these families, I thought it might be appropriate to ask some of the families I knew rather than describe what I thought they needed. I asked a group of five parents, whose children I have fairly recently supported, but who are now in Early Learning Units attached to schools for children with severe learning difficulties. I chose to ask these families about the value of early years support, thinking that they would now be able to consider those years with the benefit of hindsight.

All families said they valued the regular contact with a familiar person coming to the home. It was felt to be a much more relaxed situation for the child, to be visited in a familiar environment and also better for the parents who felt more comfortable in their own homes than in, for example, a clinic environment. Two parents said that home visiting was more convenient if there were other children in the family. Three parents said their disabled children were better able to demonstrate their abilities at home than in clinic or hospital settings.

All parents found it useful to have someone visit with whom they could share ideas about toys and activities. Suggestions for birthdays and Christmas were also very helpful. All parents valued practical help in devising play materials from everyday items that the children could enjoy and play with independently. Three parents said they were pleased to find there were lots of things they could do to help their children's play and development that they might not have thought of on their own, and that would not cost them a fortune!

Three parents said they found it useful to be able to talk through the medical implications of their children's conditions and the relevance of these to their everyday activity and level of development. Two parents mentioned their

children's visual impairment (both are registered blind) and said they were glad to have support based on professional training and experience, which had helped them to understand better the ways in which their children were responding to everyday events and activities.

All parents valued regular contact with someone who could act as a link with other agencies, other departments and with other parents. Some parents mentioned an apparent lack of co-ordination of information about disability, benefits and other services, such as respite care, to families of disabled children. It was useful to be able to ask someone about other services who would be able to find out on parents' behalf. Parents welcomed information about Disability Living Allowance, even if they felt they didn't want to claim straight away. Help with filling in the claim form was very welcome, and parents receiving benefit for their child felt it was helping to provide for their child's extra needs.

Parents were pleased to be told about educational provision available locally and some asked about out of authority provision. One mum was pleased that her son could start part-time school at two, and although other parents were keen to know about provision and the procedure for assessing their child's educational needs, they felt their children were not ready to start school at two years of age.

Several parents said they felt that relevant information about services was not available from their local health centres. One parent then added "I suppose they don't have much experience of children like mine."

Listening to parents talking about their experiences of the early years with a multi-needs child, it seemed to me that they valued practical help the most, to know that they could make a difference and help their child to make progress. They also valued emotional support in motivating them to keep going with activities when signs of progress were very slow.

Several parents spoke highly of the support they had received from physiotherapists. One mum said, "I felt so helpless in the beginning. I was glad to see anyone who could come to the house and give some kind of input or information about other children with the same condition."

Access to information was highly valued by parents; information about their children's educational progress and medical condition, being able to discuss matters with specialists, knowing which courses of action were available to them and which, if any they chose to pursue.

On a personal note, I would like to add that although my experience is not vast, it seems to me that when parents understand their children's difficulties and have the information and confidence to discuss matters with professionals, it helps them to look ahead to the future and makes for successful parent-professional partnerships long term.

Lesley Husbands - Visiting teacher, MSI, Solihull LEA

MODELS OF EARLY SUPPORT TO PARENTS AND CHILDREN WITH MODERATE, SEVERE AND PROFOUND MENTAL RETARDATION IN THE REPUBLIC OF SLOVENIA

Few events will affect parents as deeply as the realisation that they have given birth to a child with moderate, severe or profound mental retardation. They are faced with questions like: What do we do now? Where can we get support? Why us? Von Bracken and Cotandis (19971), Carr (1974, 1978), Eggert et al (1980), Thomas (1980), Bach (1979), Hackenberg (1983), Goldbert et al (1986) believe that such families are socially and economically burdened. In addition, caring for such children is different from caring for healthy children. The families face a difficult challenge; their expectations are changed, relationships among the family members and outside the family are changed, guilt feelings develop, and numerous questions about causes and consequences occur. It requires a great deal of wisdom and strength for a family to accept that their child is as he or she is, and to begin to search rationally for solutions to his or her present and future life.

In most cases, the parents want to keep a child with mental retardation at home and use day-care centres. Usually this is the best solution. The results of American studies published in the 'Headstart Program' showed that children with mental retardation from lower socio-economic backgrounds have a better prognosis if the professionals succeed in ensuring long-term specialist support for parents and if parents, under the supervision of the professionals, work with their child at home (Kane 1983, Boodman, Cecil and Baker 1984, Beller 1982, Craig and Campbell 1984). Similarly, the results of German research showed that parents can make a significant contribution to the achievements of their child (Konig 1985, Schamberger 1977, Hartsman 1982). Ohrt (1983) believes that what the parents do for their child at home remains crucial for further development regardless of the actual extent of the therapy they undertake. These families need continuous support, which differs with respect to the child's age and the stage of development.

How is support to parents with mentally retarded children provided in the Republic of Slovenia?

When considering those services which deliver support in my country, both to persons with mental retardation as well as to their parents and, at the same time integrating the wider community, I would like to single out the following three factors for further discussion.

Open public health service

All births take place in maternity hospitals and as a result the health service is the first to identify and treat children with developmental delays. It monitors those pregnancies at risk, and at the time of birth all at-risk deliveries are screened. Of all the cases followed up by professionals, 10% of children prove to have developmental delays. These are subjected to further systematic treatment. Initially, the treatment is individual and in out-patient clinics.

These children continue to be monitored by professionals in the mental hygiene department (by child psychiatrist, clinical psychologist, specialist pedagogue, speech therapist, social worker, physiotherapist, nurse) even when they have started to attend kindergartens. The transition of children from out-patient clinics to kindergartens is carried out by a team of health professionals and pedagogues who work in kindergartens. The links at this stage are close and remain so, at least during the pre-school years. This multidisciplinary team assesses a child at least twice a year, or more often if necessary. On the basis of the assessment, a programme of activities is prepared. Continuous involvement of parents is very important as every child, and every family is individual. Participation and motivation of parents is beneficial for the child's up-bringing and education.

Why do I mention the open public health service as a factor of support? Because it is accessible to all, everybody has the right to use it, and in this country it is provided free.

The health service exercises active intervention through invitations selected from the list of children. If the response is poor, home care and social workers are involved, and home visits arranged. This can be perceived as harassment, but it is believed such an approach is necessary to help the families actively through the shock they experience at the time of the child's birth. The parents are advised to include their child in the early assessment schemes within mental hygiene departments and mobile services. Families are advised to become members of the Association for Persons with Mental Retardation or the Association for Children with Cerebral Palsy. The emphasis is on encouraging communication. The effects of the public health service in providing family support are indirect. Nevertheless, it has an indispensable linking role.

Developmental kindergartens

Due to overwhelming day-to-day demands on the parents, since in most cases both parents have out-of-home employment, there is a well developed system of kindergartens both for non-disabled children as well as for children with developmental delays. The latter attend the so-called developmental kindergartens, for 5 to 8 children with mental retardation in each class. A specialist pedagogue works with the children. The group also has a nurse or carer. They work on the basis of a special programme which includes the following aspects:

- Development of independence
- General knowledge - familiarisation with the environment
- speech and communication development
- familiarisation with quantities
- Musical education
- Motor skills
- Work training - free and structured play
- manual skills

The groups are visited on a weekly basis by a physiotherapist, kinaesthetic therapist and speech therapist. These professionals work with children individually and advise the specialist pedagogue on what should be included in the daily or weekly programme for individual children. Some children are integrated into groups of non-disabled children. These models initially developed spontaneously and had no guidance from professionals. Nowadays, they are being encouraged wherever possible, and support by professionals is given to children, parents and teachers.

Why do I mention the above activity?

It is for the reason that, with the agreement of parents, a well developed network of developmental kindergartens has been set up throughout the country, which reach a high percentage of children with mental retardation. Organised care of our children has had a double aim from the very beginning: providing professional type treatment and helping the family. These aims have remained unchanged. Our children are included in kindergartens regardless of whether the parents are at work or not. Even when the parents are at home, they have the full right of inclusion of their children in kindergartens. Moreover, they are encouraged to take advantage of this service.

Seminars for parents and children

Fortunately, in spite of the difficulties at all levels of social development the care of children with mental retardation has continued to develop in Slovenia. Forms of support to families which, years ago, we had been only considering and planning for the future, or had been reading about in literature, are nowadays also available in this country. The finding of the League of Associations for Persons with Mental Retardation was that, in 1974, the majority of people with moderate, severe or profound mental retardation were excluded from systematic training. This led to the initiation of seminars for families with such children - a form of school for parents. The idea was simple: to offer, at least to some of these families, a seven day educational course to inform them about what they

could do how they could work with their child at home; to enable them to share experiences in a relaxed atmosphere; and at the same time, to organise some recreation and relaxation. The first seminar took place in 1975. Later, the content and scope expanded to such a degree that it now represents the greatest part of our programme of work.

The current overall programme of different forms of training for families with mentally retarded children includes:

- elementary seminar
- comprehensive seminar
- weekend seminars
- inland and coastal vacations

The parents are offered the seminars when the child reaches the stage of transition from treatment in out-patient clinic to kindergarten, or even earlier. The seminars are organised regionally, so that the parents have an opportunity to get to know the professionals and local associations for persons with mental retardation. Each year about 300 to 350 families with mentally retarded members attend different seminars and vacations; in total this represents about 1000 participants.

Elementary Seminar. This seminar is primarily designed for parents with pre-school children with moderate, severe or profound mental retardation. Due to its content and method of work, it is highly desirable that both parents participate, or the whole family including non-disabled children if there are other children in the family. In addition, life-important matters are health with that concern the whole family. This includes dealing with problems in the relationships among the family members which might have remained unresolved from the time of the birth of the mentally retarded child, providing advice by professionals to both parents, providing an opportunity for the families to share their experiences, and getting to know each other and mutual observation.

The seminar lasts for one week (from Saturday to Saturday) which, because of its content and for organisational and emotional reasons, has proved to be the most appropriate duration. In less time, it would be difficult to carry out all the programmes. Emotional relaxation and adjustment of parents and children to the place and methods of working needs time. A longer time, however, does not bring advantages - a more comprehensive programme would be too demanding for participants, a longer absence would make attendance impossible, and organisationally it would be difficult to provide the professionals and for parents to get leave. All children are well looked after as care by trained staff is provided.

The professionals that are usually available for discussions with parents are: a psychologist, social worker, paediatrician, speech therapist, specialist pedagogue, members of the League of Associations for Persons with Mental Retardation and, when possible, a lawyer. The seminars mainly take the form of discussions; issues should be topical and relevant both to the group and to each individual case. If an experienced psychotherapist is present who is familiar with the issues concerning persons with mental retardation and their families, issues like feelings relating to the child, relationship between the partners and other topics will be open to parents for discussion. We could say that this is a form of psychotherapy. Our experiences in this area are very good. Often all this represents for parents a virtual unburdening of guilt feelings; parents get a solution and an answer to the question 'why them'. Such therapies often make parents open to further constructive collaboration. They also help to relax tense emotional relations towards the partner, brother or sister, or therapist. The starting point of the therapy is that there is a child with mental retardation in the family. For most parents with a mentally retarded child, this seminar represents the first vacation after the child's birth. The seminar is organised in such a way that the above mentioned programmes are carried out every day, in the morning and afternoon.

During the lectures, discussions and visits to institutions for such children, the children are looked after by trained staff, so that the parents are relaxed and without worries. The leader of the seminar, the co-ordinator, is present all the time; he or she is responsible for the activities of the seminar, and is always available to give support to the parents, colleagues, visitors, observers and other participants. During the seminar there is also organised recreation. It depends primarily on the co-ordinator whether the participants will remain active all the time on the seminar work.

Among the objectives of the seminar is getting parents to participate actively in their local associations for persons with mental retardation; it is for the benefit of their own and other children that their work should be co-ordinated and organised.

The seminars are currently mainly funded by the League of Associations for Persons with Mental Retardation. The parents make a symbolic contribution towards the costs for themselves and their non-disabled children, if these are attending. Some contributions are also made by local associations for persons with mental retardation; however, their main task is to find and persuade those families to attend the seminar who need it. This is not an easy task as usually those families to whom the seminar would be the most useful find it hardest to decide to attend.

The opinion at the end of the seminars of a great majority of the participants has so far been that it was difficult to make the decision to attend, but they found the seminar so satisfactory that they would like to continue with similar work in a group of the same parents, children and professionals in the following year.

Comprehensive seminar. This seminar is designed for parents and children who have previously attended an elementary seminar and who wish to improve their level of knowledge. Whenever possible the participants and the leader of the seminar are the same as in the elementary seminar. The main difficulty - how to secure the right families - is no longer a problem as the great majority of participants in the elementary seminars wish to continue the work in the following year. There is also much less initial discomfort as most of them will have overcome this crisis during the first seminar, they will have known other families with similar problems and will have probably resolved the most crucial issues regarding children with mental retardation. They are also familiar with the methods of seminar work.

In the second seminar these are basically the same as in the first seminar, only the professionals are different and parents usually take a more active part. Clearly, the work of parents as a psycho-therapeutic group continues, and becomes more profound; it is therefore essential that everybody has similar basic experiences. Only in this way can they, on an equal basis, share their views and experiences that are often deeply rooted in the intimate feelings of individual family members or a family as a whole.

The whole programme takes one week. In addition to a psychologist, there is also present a specialist pedagogue, paediatrician, child psychiatrist, orthopaedist, orthodontist, speech therapist, physiotherapist and representatives of the League of Associations for Persons with Mental Retardation. Financing of the seminar is similar to that of the elementary seminars.

Weekend seminars. Some local associations organise shorter seminars for their members. These are 1 to 3 day seminars (at the end of the week) with programmes specially prepared for the needs of particular groups. These seminars are attended mainly by families from rural areas who find it to stay away for longer periods because of the demands of work on farms.

Vacations. One week vacations are primarily meant for families with an adult member with moderate, severe or profound mental retardation who are not included in any of the

organised forms of care or occupation. They are also attended by families with younger children who have completed training seminars.

The programme consists of different activities whose aim is to improve health, to help the participants to relax and improve their general condition. It is adjusted to the wishes and needs of the members of the group and to weather conditions. They are led by trained staff or parents who have children with developmental delays. Some professionals may be present the whole time or stay temporarily to give the parents advice regarding the upbringing of their children and other life important matters.

Conclusion

My aim in describing the above types of activities is to illustrate how children and parents can be disburdened; disburdened while putting more burden on them (by educating them by professionals). I believe that burdening and disburdening are two parts of the same process which, in practice, often cannot be separated. When they are, it is more for analytical purposes. If education is correctly based, it represents an improvement for the family, their child and his or her environment, and at the same time brings about a feeling of contentment and disburdenment. If the issues are systematically addressed, the rest somehow balances itself. Everything becomes a style of life, a professional doctrine that embraces the people in the community and local professional services.

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A Reader's Response to the SCAA Draft Document on Preschool Education

My first reaction on reading the SCAA draft proposals for Preschool Education "Desirable Outcomes for Children's Learning" was, "Well, where are we, then?" referring to the fact that the only reference to children with special educational needs was, as Barry Carpenter points out (Future Forms, December 1995), a brief sentence in the Introduction, which made the point that some children, particularly those with special educational needs, will fail to achieve the desirable outcomes that form the basis of the document, and will require further help to do so after reaching statutory school age.

The lack of reference to children with special needs is disappointing, as I had thought that we had made some progress in educating society in general and the government in particular, that we do not want a separate document on special needs, or even to be dealt with in a chapter added on to the end of a general document. What we want is to be given consideration alongside all other children, as an integral part of any debate on education. The point being that the special learning needs of all children, whether they arise from profound and multiple learning difficulties or from being particularly gifted in one or all areas, are part of the normal continuum, and therefore form part of the basic debate.

It is recognised that early education for children with special needs is vitally important, as evidenced by the fact that they are entitled to receive educational input from the age of two years. The range and quality of provision offered to many children, either in their own homes, or in mainstream, integrated or special school nurseries is excellent, and the learning achieved by many children provides the necessary foundations for future development and achievement. Without early intervention from a wide variety of professionals for pupils with profound and multiple learning difficulties, many vital years may be lost and their capacity for development may be impaired.

There is little to take exception to in the SCAA document, and the significant features of good practice are just as relevant to children who have special needs as those who do not. I particularly applaud the notions of working in partnership with parents, helping children to feel secure, valued and confident as learners, engaging in a range of activities to aid all-round development, and monitoring progress through frequent observation and assessment. There is even mention of identifying problems early on which can lead to appropriate intervention and support, but this rather bald recommendation, with no further suggestions as to how identified needs may be met within the nursery setting, leaves the reader with the impression that once identified, the realm of meeting those needs is a deep, dark and mysterious one, not to be explored in a document of this nature.

Where are the references to the wide variety of professionals who may offer their skills to those children who would benefit from them; where in the examples of good practice are examples to show how children with severe or profound learning difficulties may participate meaningfully in the activities offered; and where does it stress the importance of children learning to socialise with and show understanding for their peers from all walks of life and of all abilities?

This is a document on desirable outcomes. Let us not forget that it is a desirable outcome that children with special educational needs should be seen as a vital element within our preschool population, whose needs are considered alongside those of other pupils. Any guidance to nursery providers that does not show how children with special needs can be included within the provision, is incomplete, and sadly, serves only to maintain out-dated notions of people with special needs as being separate or different. It is time that we allowed them to take their rightful place in the mainstream of life, and what better place to start than in nursery education.

Suzanne Saunders
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January 1996

"LIFE QUILTS" FOR PEOPLE WITH SEVERE AND PROFOUND LEARNING DISABILITIES: A venture into the unknown

"You see, some folks has albums to put folks' pictures in to remember 'em by, and some folks has a book and writes down the things that happen everyday so they won't forget 'em, but honey, these quilts is my albums and my di'ries, and whenever the weather's bad and I can't git out to see folks, I jest spread out my quilts and look at 'em and study 'em, and it's jest like goin' back fifty or sixty years and livin' my life over again."

Aunt Jane of Kentucky by Eliza Calvert Hall, 1907

Arguably, one of the hardest areas to develop in working with a person with profound and multiple learning difficulty is a sense of his or her story. Our sense of ourselves and our role within a community is strongly influenced by the memory of events and our response to them. What does someone with severely limited conceptual and linguistic abilities remember of significant life events? and how could we enable them to recall and share their experiences?

Objects of reference

In recent years, we have seen advances in the use of strategies to develop anticipation and recognition of everyday routines. Through the use of objects of reference (Park 1995, van Dijk 1986) and consistent sensory cues (Park, Robinson and Williams 1989) concrete associations can help to make events meaningful to individuals. A 'scrapbook' approach has also been shown to be successful in developing topic-sharing about past events amongst non-speaking children (Musselwhite 1990). Maybe it is possible to use concrete sensory stimuli to bridge between the past and the present.

Objects of reference can either function as *symbols* which represent or stand for a concept or as indices, which "relate to the thing they stand for because they participate in or are actually part of the event or object for which they stand" (Bates 1976, p.2). For example, a cup becomes an 'index' of drinking when, and only when, it is the actual cup used in the act of drinking. It is literally part of the activity sequence. If a blind person uses a guide cane outdoors, then that cane is an index of 'going out'. A bath plug may be an index for having a bath when the person puts the plug in at the beginning and removes the plug at the end of the activity.

How can we acknowledge activities in school, and the rites of passage that come with age, for the individual with profound and multiple learning difficulties. Shantel is 16. In an attempt to bring to her attention the various changes in school, we have used the idea of index in making a variety of blankets that do not signify events as much as actually participate in them. For example, when she attends assembly she has a piece of corduroy 'blanket', about 2 feet square, on her lap. After her dinner, Shantel rests on her sackseat, underneath a mohair blanket; the corduroy and the mohair fabric therefore function as indices of 'assembly' and 'after dinner rest'.

Quilting

The blanket strategy led us to thinking about quilts. Quilting is a community tradition dating back hundreds of years, which reached its peak in 19th century America. Its function was both practical and symbolic. Patchwork quilting enabled every scrap of material - clothing or furnishing - to be re-used, and in so doing, created a family history in microcosm. Quilts made from new fabric commemorated life events such as weddings, new homes and the birth of babies. These quilts were undertaken by groups of women working communally, using traditional patterns with symbolic associations such as love knots or horns of plenty. In recent years, this commemorative aspect has come to the fore in projects such as the Aids quilts (in memory of individuals who have died). In a programme shown some years ago on TV (*Quilts in Women's Lives*), there was a most moving piece about a mourning quilt created for a mother from the clothes of her daughter, who had recently died. It was not at all maudlin, but genuinely celebratory, showing how the quilt became a creative, healing memorial.

These traditions suggest that quilting would be a particularly appropriate craft to develop with people with severe and profound learning difficulties.

- The materials are by nature sensory, offering contrasts in colour and texture.
- Scraps of clothing can be incorporated; surely the most tangible reminders of our past.¹
- There is potential for family and community involvement. Individuals with disabilities can contribute by choosing and sorting materials.
- There is potential for celebrating life, and working through grief. In principle, a family could begin a quilt during the childhood of the person, and deliberately create fabric mementoes of events which are significant.
- Real objects could be incorporated within the quilt. A symbolic continuum from index (representational object) to symbol (two-dimensional fabric) could be developed over time (see Ockelford 1994). For individuals who use and understand symbols (Rebus or Pic, for example), these could be applied as part of the pattern.

We have a dream..... A huge Arts Council grant is obtained to employ artists skilled in quilting to work with a group of people with severe/profound learning difficulties and the families, carers and schools. It leads to an exhibition in a major gallery where the owners of the quilt display what they have created

We, all right, not yet. We'll start small and realistic. Anyone who would like to be involved in an initial workshop to explore links between objects of reference and the craft of quilting, and who would like to try creating a small quilt of about 4-6 pieces - please contact us. Are there any more frustrated needlepersons out there?

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¹ *One of use once touched a piece of fabric which resulted in instant recall of walking down Godalming High Street feeling as fine as fivepence in a pink two-piece (straight skirt) in white pointed shoes (my first heels). It was a sunny Sunday evening, and I was on my way to church, this being the only place where I might possibly meet a BOY. Nothing before or since has been such a vivid reminder of how it felt to be fifteen.*

Networking through PMLD-Link

Don't forget that you can use PMLD-Link to ask for help and information from other readers when you are looking for ideas equipment and knowledge that others may have. Just write a short paragraph stating what you are looking for, and this can be put into the next issue of PMLD-Link. We send out 300 to 350 copies each time to people working in all kinds of services and from all professions as well as some parents. This should bring in some useful responses.

We would also be interested to know whether using PMLD-Link in this way has worked for you - just a postcard or a phonecall will be enough to tell us.

CONFERENCE REPORT:

Issues of Communication held at Manchester Metropolitan University on 7th February 1996.

Despite the terrible weather nearly 50 people managed to get to Manchester for this conference which was jointly organised by MENCAP and Manchester Metropolitan University. Notes were made by a number of people of all the proceedings, to be disseminated through PMLD-Link so all of you who, like me, were hoping to go but never made it, or would have liked to go but for some reason couldn't, now have the opportunity to read about the day.

The Keynote Address - Dave Hewett

Dave Hewett's address to the meeting gave ample and very effective illustration of the way in which communication activities should be approached with PMLD pupils and reflected the same essential features that he was putting forward. These were that first and foremost the activities, and the whole process of communication, needs to be made fun so that everyone including both the teacher and the pupil get enjoyment out of it, with the result that in time more effective and meaningful communication can be developed.

The process of both verbal and non verbal communication, or the lack of it were illustrated by numerous videos ranging from Basil Fawlty in his usual manner showing how not to communicate effectively with his hapless employees, to footballers being given copious instructions that no one could understand, to the obvious communication between musicians that was essential for their performance.

The role of non-verbal communication in conversation was shown, with mutual attention and responsiveness and evidence for each participant that the other is attending, as well as giving clues for turn taking were seen as important. Interpersonal attitudes, feedback and emotional reactions as well as gestures that emphasise and endorse the sincerity of what is said were all seen as essential features to effective communication.

Communication was looked at first in relation to the development of language in the first year of life and in particular the way in which mothers and babies communicate. This was shown by a mother and baby responding to each other in many ways which illustrated such things as the rehearsal of turn taking and intentionality. The quote from Stern D et al (1977) that "The Primary purpose of mother - infant interaction is for the two participants to interest and delight one another" emphasised the theme of enjoyment and that while they are interesting and delighting each other, all the other parts of the communication process will be covered. The priorities in communication were given as that firstly it should be enjoyable, secondly effective and thirdly accurate and precise. The video of Basil Fawlty communicating with Manuel in his usual manner,!!! clearly showed that none of these essential parts were present and that as a result there was little or no effective communication taking place.

Physical contact was also shown to be very important and was fundamentally irreplaceable in the early stages of communication. The need for close physical contact and all the other necessary elements of communication was illustrated by looking at a young man who very rarely got involved in communication situations and who in fact would rather play and twiddle with a "yellow thing" the type of broken toy or a part of a construction kit that so many PMLD people can develop an obsession with and go round twiddling it all and every day. To involve him in communication situations all the person concerned has to do was to make themselves more interesting than the "yellow thing" which initially would seem an easy thing to do until consideration is made of why perhaps John prefers his "yellow thing" The reason for John's preference were that it was safe and secure, does not make demands he cannot comprehend and is predictable and reliable. John also has power and control over it, and as it is simple he is an expert with it and on top of all this it is also a good companion. John had experience of people who were the reverse of his favourite "yellow thing" and so understandably he did not want to have a great deal to do with them and perhaps, if nothing else, we need to look at the demands we make on people such as John and consider whether they are able to comprehend what we may be trying to do with them.

The way in which John was drawn into a successful communication situation was illustrated and showed how technical expertise and intuition were used along with obvious enjoyment to draw him into communicating. He was allowed to be close and touch the adult working with him showing the great importance of physical contact. The experience was obviously enjoyable for John as well as being effective and accurate and precise with many rich meanings being exchanged.

The situation also showed the importance of "getting your face in the right place, wherever this may be" In this case with John it was very close which enabled John for a while to come out of his own small world where the "yellow thing" was all important into a situation where someone actually wanted to be with him in an enjoyable and mutually rewarding exchange. For a while a person was more interesting than his "yellow thing"

From this we need to remember that the teachers communication abilities are the major educational instruments in the classroom and yet how often have we asked a colleague to stand back and look at what we are doing or watched videos of ourselves or had a discussion on these lines at a staff meeting. Perhaps more than anything else the enthusiasm that Dave put into his talk needs to be reflected by everyone remembering that our priorities in communication situations should be that it is **fun and enjoyable** as well as **being effective and accurate** and that if along with this "**we get our face in the right place**" our effectiveness in communication situations will be greatly enhanced both for our pupils and also ourselves.

Reference. Stern D et al (1977) in Nind M and Hewett D (1994) Access to Communication, London, David Fulton.

Empathic Handling Dave Hewett

The workshop began by looking at a number of definitions of Empathy such as "The power of projecting one's personality into, and so fully understanding the object of contemplation" (Shorter Oxford Dictionary). There were other definitions given but the shortest and most useful was Dave's own which was "Doing your best to imagine what it feels like" and this is what we did for the rest of the workshop. We looked at what it was like for someone in a wheelchair so that we could have greater understanding and empathy with the everyday problems that are faced by our students.

The members of the workshop were given the task of sitting in a wheelchair so that they could talk about and rehearse ways of talking to, or otherwise communicating with the person who is in the wheelchair. Observations were made so that everyone could stand back, look, watch and appraise so that they could examine and evaluate the situation.

We considered a range of issues that included the best position for effective communication, what sort of position looks 'right' to an onlooker - respectful, mutual, equal, and which sort of position feels 'right' to the person in the chair, and is this the same as how it looks to the onlooker? The 'best' positions were considered by the group, and it became apparent that we have to think about principles of procedure which we can fit to various situations.

When considering 'empathic' handling a number of rules and principles were looked at that would be helpful when considering individual student's needs, and in particular those with PMLD who may lack understanding of what may be happening to them during the day. These included such general points as not approaching a person from behind and not touching them or moving them without advising them about what is going to happen. It was also felt to be important to always treat any person as communicative, even though you may be in no doubt that she or he does not understand speech.

A running commentary was also felt to be necessary which would have the effect of 'cueing in' those people who do not understand speech and reinforcing the principle that those who do not are nonetheless being treated as communicative beings. It should also have the effect of enabling staff to cue each other about what is happening and also ensure that most of the speech in the room is directed and concerned with the students in the room.

Other points that were raised were that you should 'think person rather than chair' and height and body language can cause intimidation. 'Getting the face in the right place' was again considered very important as was the use of touch when the face was not available.

Good and bad practice were also considered with members of the group experiencing what it is like to be pushed along without warning and being unable to have any control over what was happening to them. This was a very effective, and salutary lesson for everyone to be even more considerate when working with people who may be very dependent on others.

These are just a few of the principles looked at in the session, and it needs to be remembered that the atmosphere created by their application should be light-hearted purposefulness. It also needs to be remembered that the intention is to bring quality and purpose to all those things which might otherwise be routine and mechanical chores.

The last and most important of the points made with empathic handling was that time should be taken about everything, and a motto was given which everyone should remember:

"The achievement of the objective should not be more important than ensuring that there is quality in every aspect of the process of achieving it."

In our work we need to remember that "perfection may never be achieved, but it is quite easy to attempt it continuously."

The Learning Environment Leighton Reed - Royal School for the Deaf, Manchester

Leighton focused on multi sensory impaired students who have enormous difficulty in making sense of their surroundings, therefore carefully planned appropriate 'learning environment' helps to make their world safer and more comprehensible.

The seminar examined how practitioners can create an environment commensurate with the students needs. It explored the 'notion of control' and examined ways which could enable students to access their environment.

The two main topics were:

◆ **What is an appropriate environment for students with auditory and visual impairments?**

This looked at environment indications which included: Hearing Conditions, Visual Conditions, State of Health, Overhead Lighting etc. This was broken down into 5 main areas:

1. Feeling/Tactile	2. Visual	3. Auditory	4. Sensory	5. Mobility
People Markers	People (Speed of delivery when signing)	People (always talk Keep it relevant)	Tag each day of the week with a different aromatic oil.	Look at ways of giving increased/supported mobility
Sensory Area	Positioning	Centrally ambient noise	Give an. indication marker for each task	Outside referents for specific areas
Sensory Rooms	Optimum Lighting	Good acoustics	Smells as reference	Rails
Resonance Boards	Ultra Sound lighting	Level of hearing loss/type of amplification		Resonance Boards
Footspa, Vibro toys		Rewarding listening experiences		Sensory Corridors

The environment of the classroom/school/residential wings, play a large part in the individual development of each child. A whole school approach is needed, which encompasses all the areas of the environment and the sensory needs of each child, this will help the child/ren to develop. It will also help to identify if the child/ren have sensory difficulties, which can be overlooked dependent on the degree of other disabilities of the child.

◆ **How can we adapt Our School/Teaching Areas to meet the needs of the Sensory Impaired students?**

This incorporates classroom management and imagination. At the Royal School for the Deaf they have created learning corridors so that children can move through them. They consist of interactive workboards which are simple ideas of maximising the units corridors and wall space. This develops into a learning experience when children are going through the corridors to the toilets/classrooms etc. or can be used in their own right as part of the classroom activities..

This allows the children to be aware of their surrounding by allowing them to explore, and it increased self confidence. Most of the boards were developed by the R.S.D. and are not commercially bought. This means that if they get broken they can be easily replaced and you can develop interactive boards that can help a particular child develop certain tasks dependent on their level of learning, at any given time.

Handouts were given out at the seminar on how to make the learning corridors and the interactive boards, along with information on U.V. lights, light stimulation and Hearing Aids - some hints.

Leighton finished off by saying that Steven Atkins had developed ten commandments for intervention entitled 'Vision for Doing' which are very useful to helping/supporting all staff working with multiple disabled people.

The main point of the seminar was to identify the multi-sensory disabilities of the profoundly disabled child and find ways of working with the child's potential and to give him/her the maximum developmental programme in a motivating, interactive and FUN way.

Communicative Interaction in the SLD Classroom

Liz Loftus

The content of the workshop evolved from concerns about the extent to which an integrated SLD classroom is the best place to meet the communicative needs of the pupils with PMLD and what is needed to ensure that they do in fact benefit from their time in an integrated environment like this.

The discussion in the workshop focused on a number of issues, including whether all pupils receive an equal amount of staff time and input with respect to communicative interaction and whether non-verbal pupils initiate much communication anyway. If they do, how do staff respond? Questions were also asked about whether all opportunities to promote communication skills were adopted, and whether the classroom organisation and structure was flexible enough to allow for staff to respond to initiations when they are present.

In many PMLD/SLD classes it is found that more able and more verbal peers have a greater capacity to demand staff input, time and attention through initiating conversation: interrupting with unrelated topics, and frequently interjecting whilst staff are directly involved with non-verbal peers, to pose questions about the activities of staff and peers.

A number of factors were identified that contribute to a communication supportive environment which promotes communication and enables pupils to make use of and extend their communication skills. These were based round school management issues, classroom issues and flexibility in curriculum delivery.

The school management issues were that an ethos should be promoted in the school where communication is the curriculum priority and that along with this, communication underpins all other learning. Staff needed to value and promote discussion about all aspects of their work and, in particular, about communication teaching and learning. There were also felt to be implications for staff training so that understanding and awareness about communication issues, in particular for pupils with, could be promoted.

In the classroom, staff should enjoy interacting. They should also be able to recognise 'communicative behaviour' and assume that all behaviours have a communicative intent and be able to respond appropriately and selectively to communicative initiations. Along with this, there needs to be an awareness of each student's communicative behaviours and effective records need to be kept so that staff in the classroom can discuss what is being done.

There also needs to be flexibility in the structure of classroom activities which allows for such things as an adoption and use of intuitive abilities, responsiveness, communication during inconsequential times or activities, but above all there needs to be humour and fun. In the curriculum there should be flexibility of delivery that will maximise on any communicative interaction in the classroom so that the curriculum needs to be planned, structured, pertinent and responsive. The lessons should be pupil centred, creating the opportunity for new responses, but there also needs to be frequent content change. Above all, as has been noted before not only in this workshop but also in the keynote address, to make any communication activity effective it has to be first and foremost enjoyable to everyone concerned. If people can actually have fun there is a greater likelihood of progress being made.

Issues of Bereavement and Loss
Dave Bowker

Bereavement and Loss are facts of life, whether one is disabled or not. *Brandon (1992)* suggests that as well as “ordinary” life losses, people with Learning Disabilities suffer additional, specific loss relating to the way other people perceive their disability.

When a person suffers a physical injury, a natural unconscious process of healing takes place, which one hopes will eventually lead to a full recovery. However, depending upon the degree of the injury sometimes a scar will remain to become a permanent reminder of the injury. The same can be said of ‘*Bereavement and Loss*’.

Research has established there are four stages a person passes through after suffering either ‘*Bereavement or Loss*’ - these are:

• <i>To accept the reality of the loss</i>	• <i>To feel (and express) the pain</i>
• <i>To adjust to the new situation</i>	• <i>To reinvest the emotional energy</i>

However, following either ‘*a Bereavement or Loss*’ the final outcome may still leave a person with ‘scars’ and the feeling/knowledge ‘*that life will never quite be the same again*’. The initial impact of a significant loss will inevitably leave a person in a state of shock/ numbness, with feelings of guilt, disbelief, and an attempt to deny the loss. This stage is usually followed by a searching and yearning process, then a sense of disorganisation, despair and helplessness. Eventually the desire to reorganise one’s life emerges and a person will begin to look for new channels and ways of reinvesting their emotional energies.

A great deal of research has gone into the ‘emotional’ and ‘physiological’ effects of stress on the body following ‘*Bereavement or Loss*’, particularly for people with a learning disability. The loss of ‘something’ or ‘someone’ significant is now recognised as a major stressor, therefore for people who do not have good communication skills, the additional stress brought on by loss can cause behavioural changes, particular if the ‘*Bereavement or Loss*’ is not fully explained. This can best be dealt with on a one-to-one-basis by a trained counsellor. The ‘*Mourning Process*’ can be affected by many factors, a number of which are mentioned below:

• <i>Nature of the attachment (i.e. strength of bond)</i>	• <i>Mode of death</i>
• <i>Childhood experiences</i>	• <i>Inhibitions of feelings</i>
• <i>Cultural attitudes to death</i>	• <i>Meaning of religion</i>
• <i>Life crises prior to bereavement</i>	• <i>Length of relationship</i>
• <i>Degree of reliance upon the deceased</i>	• <i>Social support networks</i>
• <i>History of mental health difficulties</i>	• <i>Secondary stresses</i>

Special consideration should always be given to a number of issues surrounding the following situations of ‘*Bereavement and Loss*’:

Death of a child	Stillbirth
Spontaneous/procured abortion	Suicide
Body not found	Mode of death (witness, horrific, murder)
Gay relationships where couples are not “out”	Major disasters
Religious/cultural/family implications	Multiple losses at the same time
History of mental health difficulties/“exceptional grief reactions”	

Synopsis of workshop on *Issues of Bereavement and Loss* given as handout by Dave Bowker

Loss is a fact of life for all of us, disabled or not. It is suggested that all change involves some form of loss, and we develop coping mechanisms to help us regain an emotional equilibrium. Brandon (1992) suggests that as well as "ordinary" life losses, people with Learning Disabilities suffer additional, specific losses relating to the way other people perceive their disability.

When someone suffers a physical injury, a natural, unconscious process of healing takes place. This, one would hope, leads to a full recovery and return of original function and appearance of the injured part. However, the degree of recovery depends on many variables, including the severity of the injury and the general health of the individual. Predictable stages in the healing process can be identified, with the wound changing gradually from painful and inflamed, to healed and fully functional, maybe with a scar to act as a permanent reminder.

A similar, spontaneous, process has been identified by such writers as Colin Murray-Parkes and William Worden for "emotional" injuries, specifically around loss. Predictable responses and tasks of mourning take place, which aim to lead to full recovery of the individual. This process can be complicated by the individual differences in each person, and is further distorted by the communication difficulties experienced by many people with PMLD.

Much of the emotional healing process (or "tasks of mourning" as Worden (1991) describes them) is around the expression of feeling, in particular anger and sadness. In a person with PMLD, such expression can be observed as Challenging Behaviour, with its associated behavioural response from carers and involved professionals. On the other hand, a more covert reaction may occur and manifest itself physiologically such as appetite changes, weight loss or gain, menstrual changes or variations in established patterns of epilepsy or sleep. The individual may lose skills, including those of communication, which adds to the complexity of supporting a person with PMLD who is grieving.

A great deal of research has gone into the emotional and physiological effects of stress on the body. Loss of something or someone significant is recognised as a major stressor, therefore in people who do not communicate easily, the wide range of stress related physical and behavioural changes could well indicate a loss reaction.

If there were easy answers, we would already be using them. This presentation attempts to analyse the process of mourning as it might apply to an individual with PMLD. The essence of the work is on those closest to the individual understanding how s/he expresses feelings and communicates with the world around him/her. There are established guidelines on how to work with someone undergoing grief, which can be used effectively with some people with PMLD. However, as with many "stock" responses, the challenge lies with those who try to translate the theory into appropriate methods for these people, not only in recognising changes as possible loss reactions, but also in facilitating the healing process.

References:

Brandon, D. (1992) *Ordinary Magic* Tao Publications

Worden, W. (1991) *Grief Counselling and Grief Therapy* Tavistock

Working in Partnership with the Parents of very Young Children
Irene Westerman - National Children's Officer for MENCAP

This workshop examined a number of the issues faced by those working in education with the parents of very young children with special educational needs.

Four areas were discussed for 'partnership' between the 'teacher' and the 'parents', as listed below:

- POWER
- KNOWLEDGE
- COMMUNICATION
- TIME

POWER:

It was felt that adults in education have power, whilst children do not have either the power nor the experience and therefore are less able to develop communication skills equally. A child's progress will be diminished if parents do not feel they are being seen as partners in the educational process with the unique knowledge and information they have to impart.

KNOWLEDGE:

This can be a difficult areas; both parties usually assume the other party knows far more about the situation/child than they do. A typical example is that parents assume teachers know much more about their child's history than the teacher actually knows, equally teachers assume parents know more about the school routines and systems than they do. It is therefore beneficial to both parties to establish patterns of interaction which can result in ensuring that misconceptions and misunderstandings are never exposed.

COMMUNICATION:

The style of communication between the parents and teacher is a very powerful tool, which can help to overcome problems in 'power' and 'knowledge' or equally serve to intensify them. It is important for the teacher to develop listening skills and feedback skills when dealing with the parents.

TIME:

Time is also important when developing any relationship. Between a teacher and a parent of a child with special needs, time can be a sensitive issue as both parties will be working to very tight schedules. This can be difficult if either party is reluctant to face what can sometimes be a difficult situation. However, it has been found that if there are problems within the 'partnership' giving it more time may be the simplest step to resolving the difficulties.

FUTURE FOCUS: Using IT effectively

All of us working with people who have profound and multiple learning difficulties are concerned to provide the best opportunities for them. Developing communication must be the key issue. Research that I have carried out recently with pupils has shown ways in which Information Technology (IT) can be used effectively to enhance communication.

I have found two major problems with use of IT with this group. One is the limitations of the technology, the other is the limitations of our imaginations. By looking closely at the nature of communication, and the pre-requisites that effective communication demands, new insights can be gained as to how IT can provide opportunities for demonstrating communicative skills. It can also provide a means for people to interact with their peers in co-operative, and even competitive, games. For example, pupils with PMLD at George Hastwell School, in Cumbria, use BIGmacs¹ to play a kind of 'Simon Says' game with each other and with the rest of the class.

Another of the difficulties is determining the steps of progression and the strategies for achieving them. There are many instances of schools using IT for teaching 'cause and effect' with no real plan as to where that skill will lead. To gain contingency awareness children need consistent and reliable experiences. This means technology that *always* works. One child, learning to produce consistent responses to a stimulus, found that despite her best endeavours the switch did not always produce the expected result. This was not because she was failing, not because the switch did not work, in this case the problem was the choice of switch. The teacher had chosen a lever switch with a hinge at one end. When the pupil pressed the switch near the hinge end, of course it did not operate. This caused confusion and damaged the emerging understanding.

As well as understanding the technology and the range and types of purposes to which it can be put, we need a means of assessing the individual's current capabilities. Many of the tools available, although valuable for some purposes are not sufficiently focused as a tool for determining ways in which IT can be used. My research looks at assessment and observation in this context and I discuss a software tool designed to help in this process.

Observation is an important factor behind successful intervention. This is very difficult for teachers who are busy with catering for the complex needs of the whole class. I have demonstrated, however, that occasional focused sessions with a facilitator to assist in the observation can be well worth the extra effort and inconvenience. Small communicative signals and demonstrations of cognitive competence are easily missed in the daily routines. Once observed, however, they give important clues to potential capabilities and can inform targets for individual progression.

Tina Detheridge is undertaking the above research at Warwick University. She is also a senior lecturer in Special Education at Westminster College, Oxford.

¹ BIGmac is a speech output device distributed by Liberator, that allows pre-recorded messages to be spoken at the touch of a switch.

FRAGILE X SYNDROME: A LITERATURE REVIEW

Fragile X syndrome is the most common inherited cause of developmental and learning disabilities, and is thought to affect as many as one person in every 1,000. However, it is still a relatively unheard-of condition in the United Kingdom, even amongst those professionals who may be working with children and families who are affected by the syndrome.

The high level of incidence of the fragile X syndrome, and its hereditary nature, mean that it is crucial that awareness is raised so that affected families can receive counselling.

Professionals in the medical, education and social work fields need to work in the most effective way possible with those who have the condition and their families, so that individuals who are affected by the syndrome can be helped to develop their potential and lead happy, productive lives.

A review of all the current literature and research on fragile X syndrome has been undertaken and serves to synthesise and present current knowledge and thinking in this area in a form that is readable and understandable to the lay person. It has been found that whilst there is a large amount of information on the subject, it is largely from the USA, and is dominated by information on the medical aspects of the syndrome. Very little information exists on how people with fragile X learn or respond in a classroom setting, and there is a negligible amount of advice to help teachers to plan their classrooms or their teaching in ways that will facilitate the learning of their pupils with fragile X.

As it is likely that most schools for children with moderate and severe learning difficulties will include some children with fragile X syndrome (whether or not they have been diagnosed) it is imperative that further research into teaching strategies is carried out to enable teachers to meet the learning needs of these pupils.

The literature review is of relevance to all those who live or work with people with fragile X syndrome as it provides a succinct overview of the condition and the known characteristics exhibited by people affected by the syndrome. It also draws together existing research and knowledge relating to the treatment and education of these children which is of specific interest to teachers.

Further enquiries should be made to:

*Suzanne Saunders
Centre for the Study of Special Education
Westminster College, Oxford*

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Religious Education for All

Brown, E.

Fulton, 1996, 104 pp
Paperback £11.99.
ISBN 1-85346-392-2

For many practitioners, struggling with the stresses and strains of teaching all the areas of the whole curriculum to pupils with special educational needs, this book will come as the answer to a prayer. It has not always been easy to see how to provide access to RE, and appropriate guidance has been in short supply. Brown's book is designed to fill the gap.

As with other books in Fulton's popular *For All* series, this is a practical guide in A4 format, packed with ideas; clearly laid out; and supported with figures and illustrations. The text deals briefly with the statutory position before plunging confidently into the debate concerning access to RE for all pupils. Although this is a book aimed at the whole range of pupils with special educational needs, Brown quickly makes it clear that she intends to include pupils with profound and multiple learning difficulties in all her discussions.

Chapters 2 to 5 set RE in a whole curriculum context; discuss policy making and the creation of schemes of work; and set out the key elements in the curriculum for RE. Chapter 6 then provides 35 pages of ideas for practical classroom activities built around 7 key festivals in the calendars of the world's principal faiths. Brown offers notes about possible objectives; sensory learning experiences; suggested resources and even recipes

and instructions for making special foods and artefacts. All of these are coded with helpful faith-specific symbols and have proved instructive even to members of the faith communities involved.

These activity plans are supported, in chapter 8, by extensive notes about the tenets, practices and celebrations of the principal world religions, with invaluable glossaries for the uninitiated. Chapters 9 and 10 give suggestions for stories to support the development of religious knowledge and understanding in the context of human experience (relationships, bereavement, being in care etc.) and addresses for suppliers of a range of religious artefacts.

The book also talks about recording pupil achievement and gives an insightful analysis of the value of 'experience', too often seen in one-dimensional terms. Brown shows that it is appropriate to acknowledge progression within the concept of experience, and proposes a framework for assessment which recognises this complexity.

This book is already proving immensely popular with school staff. It offers information and inspiration in equal measure in a format which is densely packed yet accessible; varied yet helpfully consistent. The celebration of cultural and spiritual diversity is a particularly welcome dimension and the book will surely make an important contribution to any staff room resource collection.

On the Agenda

Scott, L. and *Image in Action*

Paperback, 1994, 188 pp
£22.50 inc. p&p from:

Image in Action, Jackson's
Lane Community Centre,
Archway Road,
London. N6 5AA.

This important guide to sex education for young people with learning difficulties was produced as a result of seven years of collaboration between six schools and colleges in North London and the *Image in Action* team. It provides a practical guide to policy making, planning and working with young people using drama and active learning methods. It is beautifully produced, clearly argued, and resolutely student centred.

The pack adopts a cheerful, reader-friendly, open-learning style which takes the reader from a rationale for active learning as a methodology; through policy making and evaluation; to planning and implementing a programme for sex education. This latter section forms the major part of the book, some one hundred pages of detailed material on assessment; planning classroom sessions; teaching approaches; student groupings and resources; monitoring and review. The issue of including young people with profound and multiple learning difficulties meaningfully in teaching programmes is explicitly addressed throughout this section. Many of the proposed activities are of the inevitable sensory variety, but there are other interesting and challenging ideas, like the sessions on gender identity

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which are described as part of a full year's programme of work with a group of six teenagers with profound and multiple learning difficulties.

The audience for this book will be varied. There is support here for programmes of staff development; informative guidance for governors and senior managers; as well as practical help for staff who work directly with learners. Some of the materials are photocopiable and the whole pack is exceptionally well laid out and organised. Excellent value for money, I would suggest, and a great help in developing the whole curriculum.

Richard Byers, reviews editor of *PMLD Link*.

Planning the Curriculum for Pupils with Special Educational Needs: A practical guide.

Byers, R. and Rose, R.

Fulton, 1996, 106 pp
Paperback £12.99
ISBN 1-85346-387-6

'The principles we wish to celebrate are principles of good practice', so state the two Richards – Byers and Rose – in this practical guide which will prove invaluable to all teachers as they plan the curriculum for pupils with special educational needs. This book provides an ideal companion to the earlier texts, *Redefining the Whole Curriculum* (Sebba, Byers and Rose, 1993) and *Implementing the Whole Curriculum* (Rose et al., 1994). Using firsthand

examples from schools, combined with their own innovative planning formats, Byers and Rose offer a resource book rich in helpful guidance. The added bonus with this book is that the materials are photocopiable.

Whilst relevant to classroom practice, this book offers more than 'tips for teachers'. It establishes (Section 2) first principles. Staff development activities are suggested to ensure exploration of the key concepts through whole-school curriculum development. The policy development cycle focuses upon formulation, implementation, planning and review, and takes teachers carefully through the implementation phases of this process.

This book should prove useful in interpreting the 'eduspeak' of SCAA/DfEE documents into classroom-related practice; broad consideration is given of all of the influences on curriculum development in schools (i.e. OFSTED).

The hope of many teachers is that with the new National Curriculum, we will have a period of stability and an opportunity to establish curriculum coherence, thus reducing the fragmentation of learning experiences that have occurred in recent years. Suggestions in this text regarding inter-subject links go a long way to helping teachers achieve this goal.

The advice offered is not left at a theoretical level; rather the implications for teaching and learning are followed through. Thus, in demonstrating the planning for a Curriculum Module related to Science Attainment

Target 3 (page 56), illustrations and exemplars are given for this. Assessment of this module, and sample supporting activity sheets for students in both plain English and symbol-supported text, are given.

The need for differentiation (Chapter 6) in curriculum planning is strongly supported through a series of planning and recording sheets taken directly from schools. These emphasise the reality and potential of the recommendations made by the authors. The role of the student as learner is also given centrality throughout the text, with full consideration of how, regardless of disability, every student may be engaged in an evaluation of their own learning outcomes.

The guidance offered on monitoring the curriculum should be particularly helpful to senior managers and those with specific curriculum responsibilities. Increasing pressure from OFSTED and DfEE (through legislation such as the *Code of Practice*) make monitoring and review a vital feature of the curriculum process.

Without losing the reality of educating pupils with special educational needs, this book emphasises the positive influence of the National Curriculum within the context of the Whole Curriculum. Its practical and classroom-relevant approaches will undoubtedly make it extremely popular with teachers at all phases in their careers.

Barry Carpenter is Director, Centre for the Study of Special Education, Westminster College, Oxford

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One of the Family

Royal National Institute for the Blind

Videos with booklets
£29.00 per section; £110.00 per set + £3.50 p&p from:
R.N.I.B. Education Centre,
Garrow House,
190, Kensal Road,
London. W10 5BT.

One of The Family is a series of four videos and booklets designed to inform professionals who work with children with a visual impairment and other disabilities. It is divided into four sections, each comprising a video and booklet. Each section can be studied separately, whilst the four build upon each other to provide a complete introduction to the issues involved and the practice of working with children with visual and other disabilities.

First Sight

This book and video focus on the development of vision and visual skills. They emphasise the all important fact that for many children with PMLDs who have been diagnosed as cortically visually impaired, (damage occurring in the brain or the pathways to it rather than in the eyes themselves), the ability to see can be learned. The book and video explain how sight normally develops from birth to the age of approximately four years, when a child becomes visually mature, and then shows what can go wrong to give rise to various visual defects. The video shows us children who have specific visual impairments, whilst the book backs it up with detail and describes how

different defects might cause a child to behave.

We then watch a child being visually assessed and are shown the difficulties of accurately assessing a child with many problems including visual impairment. The ophthalmologist reassuringly points out that his or her report is just one aspect of an assessment, and whatever he or she may be able to diagnose, the only true test of what a child can see and how he or she uses his or her sight is through observation of the child in a variety of familiar settings.

We are finally shown children experiencing visual stimulation in a variety of settings, some very "high-tech" but some by carers or teachers using everyday objects. Various easily made or obtained resources are shown, and the ways in which they are used provide ideas for making "seeing" fun and exciting, which is crucial for motivating the child to develop his or her visual skills.

Going My Way

Going My Way looks at mobility and shows how people with visual impairments and learning difficulties can be helped to move, explore and participate in the world around them. The book describes how mobility is much more than acquiring a set of movement skills, but relies on integration in the brain of feedback from many of the body's sense systems. Early intervention is therefore crucial, not only to develop visual skills but also to stimulate the other senses so that the child is taught to "see" or gain information about his or her world by

listening and feeling in particular. We are shown how children need to be stimulated to move and explore by having interesting objects and events to discover and how they need to feel secure and confident before they will embark on what could be for a blind person, a potentially dangerous exploration.

The video shows us children moving in the school, swimming pool and during Sherbourne Movement Sessions, as well as in a variety of everyday environments, both inside and outside. It stresses the importance of ensuring safety whilst encouraging the children to develop confidence and skills. We are reminded how different professionals as well as parents and the child can contribute to the development of the child's mobility, and the importance of teamwork is emphasised. Above all, we are reminded that mobility and access are vital to a child's overall development.

Making Contact

Making Contact is about the development of communication skills, which are crucial in enabling a child to control his or her environment, to make social contact and to enjoy interactions with others. We are reminded of the importance of the relationship and activities that are carried out between a mother and her baby in establishing early communication and of how sensory disabilities, including loss of vision, can distort and delay this early learning, making specific intervention crucial if the child is to be able to learn to communicate effectively.

reviews *reviews reviews reviews*

The book gives a very useful breakdown of the stages of Preintentional Communication, Intentional Signalling, Referent and Symbolic Communication. It explains how the visually impaired child may behave in each stage, and gives ideas for teachers and parents to use in encouraging the child to move successfully through these stages.

The video shows children who are communicating at these different stages, and how they are being helped and encouraged to develop their skills. At all stages the young people are encouraged to interact with their environment in order to achieve or do something that is relevant and pleasurable for them, thus ensuring that their motivation to communicate is maintained.

That's What It's All About

This final book and video explore the issues of play and its importance for development, and of social and leisure activities which enhance the lives of all people. The book describes different types of play, while the video shows children learning through a variety of play activities which are encouraging them to reach out and explore their environment, and to enjoy interactions and contact with others.

The importance of the adult in facilitating play for children with visual disabilities and learning difficulties is emphasised. Guidance is given to the adult who must learn how to become an extension of the child, to empathise and to open up the play activity

rather than dominating or imposing his or her own ideas of what the child should be getting out of it.

The book tells us that the aims of play in the early years for children with profound learning difficulties are: to give experience of pleasurable interactions; to encourage awareness that something exists outside the child's own body; to give a sense of self and other; to develop the ability to "act" on the world; and to enjoy a range of first-hand experiences. It goes on to describe ways of playing that can fulfil these aims, and the video provides a rich variety of examples that can be followed or adapted.

Review

One of The Family is an excellent resource for all those working with children with visual impairments and other disabilities. It provides a great deal of important basic information in a way that is concise, clear and easy to understand, and the information is easily and enjoyably absorbed, thanks to the video and booklet format.

The booklets offer factual and background information and are successful in conveying sometimes complex information simply and clearly. Though short, they are loaded with content that is easily accessible and can be referred to again and again. The videos illuminate the information and bring it to life by showing real children, parents and professionals engaged in the activities described in the booklets. The educative value of seeing experienced people working in successful and creative ways is vast and 15

minutes of video (each is approximately 15/20 minutes) can teach more than the longest book about how to handle, relate to and enjoy the company of the children.

The series is aimed at professionals. It provides background information, practical ideas and insight that is equally applicable to all professionals. However, I think it is also useful for parents and extended families, all of whom wish to understand and help their child to progress and develop. The atmosphere of the series is optimistic, cheerful and fun. Above all, it stresses that progress can be made, relationships can be built and obstacles overcome.

One of the Family would be an invaluable resource for all schools who are teaching pupils with visual impairments and learning difficulties. It could be used with new or existing staff, and ideally with teachers, therapists and parents learning together. It informs, entertains and provides material for discussion regarding the curriculum, classroom practice and the use and acquisition of resources. Perhaps most importantly it helps the viewer to understand the child with visual disability better and to appreciate the world in which he or she lives. I would be surprised if anyone studying the series did not learn something from it, and I'm sure that it will lead to improved practice.

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

BOOKS

HIV and AIDS and People with Learning Disabilities These three booklets have been revised and updated.

Book 1 - What you need to know about HIV and AIDS

Book 2 - A guide for parents

Book 3 - Guidelines for staff and carers

Available from BILD, Wolverhampton Road, Kidderminster, Worcestershire DY10 3PP

Interactive Approaches to Teaching: A Framework for INSET by Mark Collis and Penny Lacey published by David Fulton. Publication date May 1996.

Whose Choice: Contentious issues for those working with people with learning difficulties edited by Judith Coupe O'Kane and Juliet Goldbart published by David Fulton. Publication date June 1996.

Enabling Access: Effective Teaching and Learning for Pupils with Learning Difficulties edited by Barry Carpenter, Keith Bovair and Rob Ashdown published by David Fulton. Publication date October 1996.

Learning through Interaction: Technology and Children with Multiple Disabilities edited by Nick Bozic and Heather Murdoch published by David Fulton 1996.

Getting in touch: finding ways of working with people with extensive support needs. by Phoebe Caldwell published by Pavilion Publishing. Publication date Spring 1996.

Fragile X Syndrome: A Literature Review by Suzanne Saunders, available from Centre for the Study of Special Education, Westminster College, Oxford OX2 9AT Tel: 01865-247644

Health-related resources for people with learning disabilities published by the Health Education Authority, available from HEA Customer Services, Marston Book Services Ltd., PO Box 269, Abingdon, Oxon OX14 4YN

RESOURCES

Information

Planet Play Leaflets. Seven play leaflets covering a variety of topics about which people frequently ask for information. Price £3.00 for the set of seven, available from Planet, Save the Children, Cambridge House, Cambridge Grove, London W6 0LE Telephone: 0181-741-4054

Planet Resource Pack Information and advice for everyone concerned with play, leisure and recreation for people with disabilities. Price £3.00 from Planet, Save the Children, Cambridge House, Cambridge Grove, London W6 0LE Telephone: 0181-74104054

Scope Leisure Resource Centre is in Redditch and is open (by appointment) to anyone interested in leisure for people with disabilities. Further details from Nick Lee or Lesley Butcher at Scope Leisure Resource Centre, Scope, Shapland House, Clews Road, Oakenshaw, Redditch B98 7ST Telephone: 01527 550909

Equipment

The Aroma Safe Box A handcrafted wooden box containing 12 high quality essential oils selected for their low toxicity and safe use. Available from Jade College of Natural Therapy, 12 Jenkyn Road, Wootton, Bedford MK43 9HE

Tocki glitter tubes available from Tocki, Unit 9, Kiln Beck Business Park, Annie Reed Road, Beverley HU17 0LF Telephone: 01482 865630.

Video

Massage Vol. 2 - Full body massage Contains details of all the elements of a full body massage. Used in conjunction with Vol. 1 it provides a varied exposition of contemporary massage methods. Available from Jade College of Natural Therapy, 12 Jenkyn Road, Wootton, Bedford MK43 9HE

Software

Make it Happen 1, 2 and 3. (PC Windows) Graduated programs that can be used for assessing visual attention, control skills, contingency awareness and some basic cognitive skills. Graphics are fairly age independent. £17.50 each

Choices (PC and Archimedes) Create your own activities for pupils with individual needs. It can provide a way for a pupil who can press a switch to indicate choices, and to record feelings of achievement. Can be used for a wide range of tasks for cognitive development. £35.00

Signpost (Archimedes) Multimedia program that introduces basic signs and symbols in a simple storybook setting. Particularly suitable for older pupils. £35.00

All produced by Widgit Software

TRAINING: Courses/Conferences 1996

- MAY**
- 1st and 2nd Aromatherapy
Two day course on the use of aromatherapy with people with learning disabilities
Run by: Playtrac Training Consultants
Tutor: R.D. Muga
Venue: Playtrac Training Suite, Harperbury, Herts
Further details: Playtrac Training Consultants\
Tel: 01923 854861 x 4385/6
- 2nd Innovative Approaches to Providing Day Activities for People with Learning Disabilities
Issues in the delivery of meaningful day activities for people with learning disabilities. Wide range of topics to be covered.
Run by: Forum on Learning Disability (RSM)
Venue: Royal Society of Medicine, London
Further details: Lisa Spicer, RSM, 1 Wimpole Street, London W1
Tel: 0171-290-2988
- 7th Improved tests for Screening and Assessments of Visual Impairment in Children
New diagnostic techniques of visual assessment which will enable orthoptists, low vision specialists and teachers for the visually impaired to gain a greater degree of accuracy in their assessment work. Cost £75.50
Run by: RNIB
Speaker: Lea Hyvarinen (University of Helsinki)
Venue: New Cobden Hotel, Birmingham
Further details: Mark Gray or Heather Pearce
Tel: 0121-643-9912
- 7th and 8th Sexality and sexual health issues for women with profound learning difficulties
Run by: Horizon NHS Trust, Harperbury Hospital
Further details: Playtrac Training Consultants
Tel: 01923 854861 x 4385/6
- 15th RNIB Music Day
Music for people with visual and learning disabilities. Seminars on a range of topics plus exhibition of resources. Cost: £15-20 (staff and carers)
Venue: Liverpool
Further details: Simon Labett
Tel: 0171-388-1266 x 2300
- 16th Getting it Clear: Accessible Information for People with a Learning Disability
Run by: Westminster College, Oxford and MENCAP
Venue: Westminster College, Oxford
Further details: Helen Smeed, MENCAP
Tel: 0171-696-5551
- 16th RNIB Leisure Resource Day
Exhibition of resources and presentations about aspects of leisure, participatory activities, opportunities for informal meetings. Cost £2.00 per session for presentations and participatory activities.
Venue: Liverpool Football Club
Further details: Charlotte Long or Gill Levy
Tel: 0171-388-1266 x 2275 or 2449

20th Sex Education for Young People with Disabilities
A practical one day course based on the materials and methods developed
by Image*in*Action
Run by: Image-in-Action
Led by: Image-in-Action team
Venue: Jackson's Lane Community Centre, London N6
Further details: Image-in-Action
Tel: 0181-340-5226

20th and 21st Stimulating the Senses
The role of the senses in enhancing the lives and communication
abilities of people with profound and multiple learning disabilities
Run by: Playtrac Training Consultants
Tutor: Irma Mullins
Venue: Playtrac Training Suite, Harperbury, Herts
Further details: Playtrac Training Consultants
Tel: 01923 854861 x 4385/6

JUNE

3rd and 4th Movement for people with profound and multiple learning disabilities
Opportunities to experiment and explore new sensations and qualities
of movement.
Run by: Playtrac Training Consultants
Tutor: Charlotte Wilmer
Venue: Playtrac Training Suite, Harperbury, Herts
Further details: Playtrac Training Consultants
Tel: 01923 854861 x 4385/6

5th Art - the value of mark making
Practical activities which underline the value of mark making. Discussion
of the processes involved and developing individual and group activities.
Run by: Playtrac Training Consultants,
Tutor: Irma Mullins
Venue: Playtrac Training Suite, Harperbury, Herts
Further details: Playtrac Training Consultants
Tel: 01923 854861 x 4385/6

8th The Future for People of all ages who have PMLD
Run by: CATALYST
Keynote speaker: Flo Longhorn
Venue: Central London
Further details: Catalyst
Tel: 01483-223707

11th Drama for people with profound multiple learning disabilities
Games, exercises and drama activities. Discussion of practical and
theoretical considerations, adapting activities to meet specific needs.
Run by: Playtrac Training Consultants
Tutor: Noelle Blackman
Venue: Playtrac Training Suite, Harperbury, Herts
Further details: Playtrac Training Consultants
Tel: 01923 854861 x 4385/6

- 12th Assessing communication
How to assess and develop the communication skills of people who are pre-verbal.
Run by: Playtrac Training Consultants
Tutor: Charlotte Wilmer
Venue: Playtrac Training Suite, Harperbury, Herts
Further details: Playtrac Training Consultants
Tel: 01923 854861 x 4385/6
- 15th Sherborne Foundation Basic Introductory Course
Level 1 Part 1
Run by: Sherborne Foundation
Led by: Stephanie Lord and Beata Gawthrop
Venue: Heathermount School, Ascot
Further details: Sherborne Foundation Centre
Tel: 0117-961-0010
- 20th Observation skills
Practice and discussion of techniques of observing and recording and how to use the information constructively.
Run by: Playtrac Training Consultants
Tutor: Noelle Blackman
Venue: Playtrac Training Suite, Harperbury, Herts
Further details: Playtrac Training Consultants
Tel: 01923 854861 x 4385
- 22nd Sherborne Foundation UK AGM
Sessions which focus on PMLD (morning) and Autism (afternoon).
Sherborne Centre, Bristol
Further details: Sherborne Centre
Tel: 0117-961-0010
- 25th Sex Education for Young People with Disabilities
A practical one day course based on the materials and methods developed by Image*in*Action
Run by: Image-in-Action
Led by: Image-in-Action team
Venue: Dialstone Centre, Stockport
Further details: Image-in-Action
Tel: 0181-340-5226

JULY
2nd

Loss and bereavement
Recognition of areas of loss within the lives of people with learning disabilities and difficulties around these issues. Stages of the grief process and practical ways of providing support.
Run by: Playtrac Training Consultants
Tutor: Noelle Blackman
Venue: Playtrac Training Suite, Harperbury, Herts
Further details: Playtrac Training Consultants
Tel: 01923 854861 x 4385/6

3rd to 5th Pro-active approaches to working with people who challenge
Course for parents and service providers who have experience of challenging behaviour in people of all ages.
Run by: Playtrac Training Consultants
Tutor: Andy Battell
Venue: Playtrac Training Suite, Harperbury, Herts
Further details: Playtrac Training Consultants
Tel: 01923 854861 x 4385/6

AUGUST

30th to 1st Sept World Congress on Rett Syndrome
"Hand in Hand with Rett Syndrome"
Gothenburg, Sweden
Further details: Congress President, Anita W-Ljungberg,
Box 259, S-791 26 Falun, Sweden

SEPTEMBER

12th Sherborne Foundation Basic Introductory Course
Level 1 Part 1
Run by: Sherborne Foundation
Led by: Bill Richards
Venue: Rolle Campus, University of Plymouth
Further details: Sherborne Foundation Centre
Tel: 0117-961-0010

16th to 19th *bild* Annual Conference - Working in Partnership with Service Users
Major forum for collaboration between researchers, professionals, carers and people with learning disabilities
Venue: Swansea
Further details: Liz Howells, Conference Administrator
BILD, Wolverhampton Road, Kidderminster, DY10 3PP
Tel: 01562-850251

25th Leaving home
Opportunities to explore the issues involved in preparing and supporting an individual leaving the family home.
Run by: Playtrac Training Consultants
Tutors: Noelle Blackman and Irma Mullins
Venue: Training Suite, Harperbury, Herts
Further details: Playtrac Training Consultants
Tel: 01923 854861 x 4385/6

OCTOBER

18th to 20th Sherborne Foundation Gathering
Further details in the next issue of PMLD-Link or from
Sherborne Foundation Centre
Tel: 0117-961-0010

NOVEMBER

2nd Sherborne Foundation Basic Introductory Course
Level 1 Part 1
Run by: Sherborne Foundation
Led by: Elizabeth Marsden
Venue: Aberdeen University, Scotland
Further details: Sherborne Foundation Centre
Tel: 0117-961-0010

TRAINING

Training Packs

Dental Health and Diet for people who have profound and multiple disabilities. A workshop training package n support of parents and carers by Alex Crawford, Hazel Andrews and Helen Mount. £45.00 (inc. p&p) Available from Mencap PIMD Section, Piper Hill School, 200 Yew Tree Lane, Northenden, Manchester M23 0FF. Telephone: 0161-998-4161

Long Courses

Professional Development Diploma in Therapeutic Horticulture

Horticultural Therapy in conjunction with Coventry University

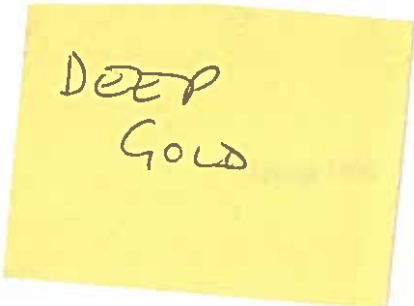
3 Module, 30 week course on day release basis. open to those with degree or diploma in Occupational Therapy or Horticulture.

Applications to: Admissions and Placement Unit, School of Health and Social Sciences, Room A116, Coventry University, Priory Street, Coventry CV1 5FB Tel: 01203 838634

Picking up the Signals: on Course for a Better Life

Manchester University, Royal Schools for the Deaf (Manchester) and MENCAP
For all potential supporters of severely disabled people to enable them to recognise and work with people with sensory impairments and the whole range of disabilities

Further details: Leighton Reed, Royal School for the Deaf, Manchester
Tel: -161-437-5951



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