

# PMILD LINK

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

## CONTENTS

Editorial	Carol Ouvry	1
Working with the Parents of Children with Complex Needs	Gudrun Spencer	2
Family Mapping as a Research Instrument	Sue Saunders	4
PAMIS: Working in Partnership with Parents	Loretto Lambe	6
Working with PAMIS: A parent's perspective <sup>1</sup>	Kathleen Murra	11
Twins and the Family	Suzie Mitchell	14
Personal Reflections	Maggie Morgan	17
National Year of Reading: Mencap Parents' Pack for Children and Adults with PMLD	John Lawson Maggie Morgan	20
Mencap's National Focus Group	Maggie Morgan	22
Information on Mencap's Family Adviser Services	Rachel Raymond	23
Family Workshop Day at Cheltenham	Jo Sullivan	25
<b>Conference News</b> Communication for All	Jo Egerton	26
<b>Future Focus:</b> Equal Opportunities and Ethical Issues	Judith Cavet	27
<b>Publications and Resources:</b>		
Reviews		29
Resources		30
<b>Inservice Training</b>		
Courses and Conferences		31
Exhibitions		32
Longer Courses		32

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

This issue focuses on working with families in many different ways. There are more than the usual number of articles, and they give us a variety of perspectives on the topic. Sue Saunders explains how a college course encouraged her to carry out a family mapping exercise, and the benefits it brought to her understanding of her work; Suzie Mitchell brings a totally different perspective with her discussion of the implications of having twins. A number of organisations, large and small, explain how they work, and what they offer to families with children or adult members with PMLD. Most importantly, we also have the views of one parent about one of these organisations, and the effect it had on her life.

Our next topic is one which is constantly part of our work, but can be a challenge to us in many ways - that of equal opportunities and ethical issues. Judith Cavet introduces the topic in Future Focus, and invites you all to write in about the dilemmas you have encountered, how you have tackled them, and whether you have found a solution, or are still in the process of working things out. This, above all, is a topic where there are few, if any, permanent solutions but there is a constant need to try to find the best ways of providing equal opportunities, and a service based on ethical principles.

***BUSINESS MATTERS******Articles:***

Material to be included in the next issue should reach me by the middle of August. If possible, can you send articles with good margins in single line spacing printed on one side of the paper only. Illustrations are welcome, although photographs are difficult to reproduce well. I look forward from hearing from you with your contributions!

Carol Ouvry  
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## *Working with the Parents of Children with Complex Needs*

To explain the ethos and role of **One Hundred Hours** properly, we first hand over to a parent with whom we have been working since 1995:

"This is our son John.

He is now two and a half years old and a very lovable and happy little boy in spite of his severe problems relating to his very difficult premature birth.

"His needs are very complex, including quadriplegic cerebral palsy, he is registered blind, has hydrocephalus and he is now fed through a tube through his stomach. He needs constant supervision, attention, stimulation and lots of love, with a sense of humour and a positive attitude.

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"We met **One Hundre Hours** the day we brought John home from the neonatal ward after five months fighting for his life. With the help of our OHH keyworker, we started to understand John's problems and our confidence grew. Thanks to all the information and ideas, we became confident partners with other professional services and could articulate John's needs and best interests.

"Our main needs are to overcome our 'disability as parents' and discover ways of recharging our limited batteries. We need to maintain our relationship as husband and wife and not lose our self-esteem, confidence and the ability to enjoy our life or the courage to try new challenges. The value of **One Hundred Hours** is that it helps parents find a way forward using their own strength and the love within the family."

We have not used John's real name, but the story is genuine enough. John has very complex needs and like so many families in John's family's position, his parents felt they were left without support from the expected sources after the diagnosis of John's complex needs.

The OHH keyworker visits John's family in their home for about two hours each week, but maintaining the flexibility they need to fit in the sessions with John's many other appointments and their own commitments.

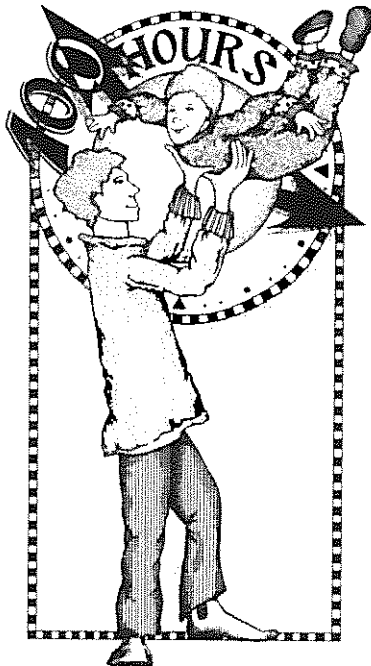
When the keyworker first started visiting three years ago, John was in and out of hospital, the precise nature of his problems were unknown, his parents were getting very little



sleep. Their keyworker was able to offer the emotional support they wanted and advocacy to access essential services.

Generally, the service they want from us is less intense now although recently the keyworker has been providing more support through the pregnancy of their second child and with John's Educational Statementing. John's parents have developed a very strong bond with their OHH keyworker and he continues to visit them as often as they need.

Technological advances mean that more babies are surviving who have complex needs, but parents are often dismayed to discover that there is very little help for them when they get their baby home from hospital. Parents across the UK speak of feeling alone and abandoned at this time. If they are lucky there will be an outreach nurse and a physiotherapist for the baby, but all too often no one asks them what *they* need as parents.



helping  
families  
of babies  
and  
young  
children  
who  
have  
complex  
needs

One Hundred Hours has developed a support system which it can offer to families in West Yorkshire and environs. We provide a keyworker who visits families every week in their home right from the first suspicions of complex problems or diagnosis, up to when the child is a couple of years old. The service is free to families and is led by them - how they use it is up to them. Generally, the keyworker offers a combination of emotional support, information, advocacy, and supporting the parents in getting to know their new baby and learning to care for him or her and play with him or her.

### One Hundred Hours

On a national level, we run a campaign, led by our newsletter *Opportunity* to spread information about the need for parent support, and supporting organisations who want to develop their own services. To this end, we are holding our first national conference, for both parents and professionals in November of this year and launching a national survey, the SOFTY survey, to examine support provision for parents in the first two years after the disclosure of suspicion of their child's complex needs.

For parents who want to influence their own local services, to encourage them to do more in the way of parent support, we offer a free service called Footprints. Footprints enables groups of parents to get together and communicate effectively with health professionals about their own needs and desires in terms of service provision. In this way, we hope to enable parents to influence the services that are provided for the families following in their footsteps.

For more details of the One Hundred Hours keyworker service, please contact Peter Limbrick on 01706 819200. For a free copy of *Opportunity* or any other of the services mentioned please write to Gudrun Spencer, One Hundred Hours, PO Box 5541, Kings Heath, Birmingham B14 7EB or telephone her on 0121 441 1580.

## *Family Mapping as a Research Instrument*

During 1996 and 1997 as part of a Certificate of Advanced Studies at Westminster College, Oxford, students were asked to consider family mapping as a research tool. As we, the students, were studying the child as part of the family in the wider context of society, this seemed an excellent means by which the family could define themselves without having anyone else presume anything on their behalf. I therefore decided to use it as part of a case study which looked at a family in some depth.

The family I studied, like so many, was not easily defined as there were several members, some living at home, some not. There were children of this marriage as well as children of previous marriages, various grandparents, uncles, cousins etc. as well as close family supporters, all of whom had their role.

Knowing this to be the case, I asked permission of a family who I knew in a professional capacity to interview each of those living in the household, in turn, confidentially. Central to all this was the fact that they had very recently received the news that the youngest member had been diagnosed as having severe special needs, so their experiences of who had been supportive and helpful were particularly acute at this time.

What each family member was asked to do was to put the youngest child and whoever else they felt appropriate, into a central shape representing the core family. Beyond this they put a wider boundary containing people who they felt were supportive, or who worked in partnership with them; this was identified as the wider family. This was an instant visual tool which could very naturally lead to comparing and contrasting where each family member felt themselves and the others to be.

From the point of view of a professional working with the family this proved a very useful exercise. It was possible to see at a glance who was considered to be close, and where the similarities and differences lay for each family member interviewed. Positional placements on the map naturally led into looking at reasons for these placements, and then each family member interviewed began to define what constituted support for them. The closer the position of the family member to the centre of the map; the greater the importance of their contribution to the family. Thus the importance of factors which have been established by other research, such as being given time, being provided with information, being offered practical help, etc. were very simply and quickly prioritised by the family members. Differences in how family members perceived each other were also evident, information which needs to be carefully respected by professionals and used sensitively in order to strengthen family relationships rather than weaken them.

Historical factors were found to be significant, emphasising that families bring with them their unique social context, experiences and relationships. Relationships which have already been defined as supportive or un-supportive were reinforced in the light of the new experience of discovering the youngest child had special needs.

The family members, in looking at the wider social network in which they considered themselves to be functioning, began to include other people on the map; those who had some part of play in the life of the family, and they placed them in relation to the family core. This meant that again at a glance one had a measure from the family members of how supportive professionals, friends, colleagues, and other members of society were felt to be. One could then again look at why they had been placed there. From this, one could begin to determine from the family what factors would have brought them closer to

the family core and begin to determine what families really value in order to help them work more coherently. This can then influence new practice by professionals.

An advantage of the family mapping exercise was that each family member defined their role for themselves. There was no way anyone could put them anywhere except where they felt themselves to be, thus respecting each of them as individuals, and defining relationships in their own terms. It gave voice to members of the family who often are given lesser roles than others; fathers, brothers and sisters, and could have included grandparents or other family members on request. Again, speaking to family members first hand reinforced some major findings of other research; that fathers often feel marginalised and siblings overlooked. This was then reinforced by where they positioned themselves on the map in relation to the child with special needs. The writer or researcher is an objective observer at this point and leaves aside any preconceived ideas they may have of what constitutes this or any other family, or who is supportive, how, or why.

One unexpected development which had not been part of the original plan, was that each family member wanted to put some people outside their support structure, and then give reasons. As an example, the mother felt society made life more difficult for her by attitude and behaviour encountered, and the non-acceptance of her child. This exercise gave her an avenue to express this, as well as throwing up for the researcher some new, unexpected information to pursue. People one might have considered to be family members were also put in this 'outside' role, and some people who were not blood relatives were included with family.

The greatest advantage I felt as the privileged mapper and as a professional working with the family, was the depth of information I was given, and the deeper insight this gave me into the perceptions of the family of themselves. I received an instant picture in diagrammatic form which was then supported by evidence, unique to that family; a reflection of what ethnographic research should be. This must be of value to professionals and all who genuinely want to offer support to families with a child with special needs.

Family centred models of intervention which recognise the importance of the relationships of all family members and the child can only benefit from any instrument which increases their understanding of the ways in which families work together, within their own society and structural context. Each family will define its own uniqueness; is considered to be important in its own right; and valued as holding the important information about themselves. This endorses the validity of the family mapping as a strong, transdisciplinary tool which puts the family as researched at the heart of the research project.

Sue Saunders  
Pre-school Teacher-counsellor  
Oxfordshire

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*NEWS about .....*

**Sherborne Foundation UK** is moving temporarily to:  
1 The Vale, Pucklechurch, Glos BS16 9NW  
Tel & Fax: 0117 937 3647  
e.mail GandCHill@aol.com

## PAMIS: WORKING IN PARTNERSHIP WITH PARENTS

In Future Focus, PMLD Link Issue no 29, Barry Carpenter (1998) questions whether we consider the whole family, the extended family, or just the parents when organising our services and events. He also queries if the parent/professional partnership is a true partnership. Although I have used the term 'partnership with parents' in the title of this article I will try to address the wider family involvement questioned by Carpenter. In PAMIS (Profund and Multiple Impairment Service) we strive to ensure that the partnership is an equal one and we follow an agenda set by the parents, or more correctly the families themselves. PAMIS is a voluntary organisation working with and on behalf of people with profound and multiple learning disabilities (PMLD) and their caregivers. In the main the caregivers involved with us are parents, wherever possible both mother and father. However, in a number of instances the prime caregiver is a grandmother, sister, brother, aunt or sister-in-law. We always issue an invitation to the caregivers to include other family members, a friend or advocate in the various initiative we are running. Again, from time to time and depending on the nature of the activity or event, families take up this offer.

### *What is PAMIS and How do we Work with Families ?*

We are a and registered charity set up specifically to work with people with pmld and their families. We are very clear that this is the population around whom our services are planned. Although families with a more able member with learning disabilities are welcome to participate in our activities the focus remains on pmld. This is at the expressed wishes of parents - see Lambe (1998). At present PAMIS is working principally in three areas in Scotland, Tayside, Greater Glasgow and Highland although families from other areas can and do become involved in our activities. The workshop programme, described below, is also being implemented in Northern Ireland in association with the Institute for Counselling and Personal Development, and a number of our European colleagues are undertaking similar work through their involvement, with PAMIS, in the *Euforpoly Project* (see below).

The principal aims of PAMIS are to:

- *provide practical support to people with pmld and their carers in order to enhance the quality of their lives*
- *empower parents and carers to influence service provision and to gain better access to community resources*

Our aims are achieved through a programme of work which includes training workshops for families, parent/professionals consultative groups, and support and advice to individual families. The topics for the training workshops were identified

by families following a lengthy consultation process. The subjects tackled by the consultative groups, known as Special Interest Groups (SIGs), are also chosen by the families. The support and advice to families is of course given in response to expressed need. PAMIS has a small core staff consisting of a Projects Director, three regional Co-ordinators, an Administrator and a Leisure Development Worker. Other professionals are involved in delivering the programme of work on a sessional basis or as volunteers.

### *Projects and Initiatives*

The following are the projects and initiatives currently run by PAMIS.

- ✧ *Training Workshop Programme*
- ✧ *Creative Arts & Profound Disability*
- ✧ *Ageing Matters: Distance Learning Pack*
- ✧ *Euforpoly Project: Training for Parents & Front-line Staff*
- ✧ *Healthcare of Women with Learning Disabilities*
- ✧ *Special Interest Groups*
- ✧ *Leisure & Profound Disability*

All of these have been developed and designed in consultation with parents and family carers. Some of the projects, for example, the workshop programme, women's healthcare and the ageing pack are run in association with *Enable*, which is the largest organisation concerned with learning disability in Scotland. The 'Ageing Matters' pack was developed in collaboration with BILD and the Hester Adrian Research Centre (HARC), Manchester. Enable is primarily a parent led organisation whereas BILD and HARC are more professionally based. A description of the various projects is given below. Further details on any of these can be obtained by contacting the PAMIS office in Dundee, address at the end of this article.

#### *Workshop Training Programme*

The aims of the workshops are to empower parents and carers by giving them up-to-date information and training on topics of concern to them, and to improve the quality of life for their pmld daughters and sons. The emphasis of the training is always on **practical** help and advice and as much as possible this is tailored to individual needs. The workshop programme follows on from a very successful series of workshops developed for Mencap (see Hogg & Lambe 1998 and Lambe & Sebba 1988). The PAMIS programme goes a stage further than the earlier project by taking up issues raised during the workshops and following these up with both the parents and the relevant professionals and, if necessary, actively campaigning to effect change. This forms part of the work undertaken by the Special Interest Groups. Topics in the programme are set out in the Table on the following page.



Workshop Topics		
covered to date:		yet to be covered
<i>Physical Management in the Home</i>	<i>Epilepsy: Understanding &amp; Management</i>	<i>Sexuality &amp; Personal Development</i>
<i>Communication, Eating &amp; Drinking</i>	<i>Management of Difficult Behaviours</i>	<i>Personal Transport</i>
<i>Planning for the Future: - legal, financial and residential options</i>	<i>Stress Management for Carers</i>	<i>Sleep Problems: Understanding &amp; Management</i>
<i>Dental Care , Diet and Healthy Eating</i>	<i>Vision: Seeing, Knowing and Understanding</i>	<i>Dressing Matters</i>
<i>Leisure Activities</i>		
<i>Effective Campaigning</i>	<i>Making &amp; Enjoying Music</i>	

The workshop are evaluated and modified in the light of participants' comments. Each topic is run at least once in the three areas where PAMIS operates and also in Northern Ireland by the Institute of Counselling and Personal Development. All presentations are complemented by written materials contained in participants' packs. These include detailed notes and descriptions of the individual sessions, guidelines on how to access local and national services related to the topic, information on statutory rights to specific services, references and further reading, useful addresses and a glossary of terms. It is planned to publish some of these materials either in packs and/or books and pamphlets. Although the focus of the workshop is generally the pmltd person, some of the topics are solely concerned with the parent or carer, for example *stress management*. Other topics, whilst concentrating on the person with pmltd also deal with the needs of the carer, such as *physical management* which has sessions on self-care, *dental care* aims to improve the dental health of all family members and the workshop on *future planning* looks at the financial needs of the whole family. In this way we try to ensure that both the emotional and healthcare needs of the family as a unit are considered

### ***Special Interest Groups***

The issues tackled by the SIGs are varied but have one aim, that is, that they should be achievable and will benefit people with profound and multiple disabilities and their families not just individuals. A specific area or topic of concern is raised by a member of the group and once agreed an action plan is drawn up by the group as a whole. Individuals then take responsibility for specific tasks and if successful the achievement is documented and shared with other interested parties.

Examples of campaigning issues are, design of supermarket trolleys for people with disabilities, changing facilities in public toilets, safety in transport, accessible play and leisure equipment in public parks, and inclusion of families *as a right* in local authorities' planning processes. Considerable success has been achieved on a number of these fronts, but much still remains to be done. *Factsheets* on some of the issues have been produced with the aim of using these to bring about change in other areas of the country.

### *Leisure for All Project*

This is a new PAMIS project supported by a BBC Children in Need grant. It is a three year project with the remit of identifying the leisure needs of both pmlD people and their families. A Leisure Development Worker has been appointed who will work closely with our three regional co-ordinators. Raising awareness, particularly that of leisure providers, of the need to consider both physical **and** intellectual access to community leisure resources will be central to the work of this project. We would be interested to hear from others working in this area to exchange and share information.

### *Creative Arts Pack*

The pack, which focuses on the creative arts is nearing completion.. The sections include *Sensory Activities, Visual Arts, Experiencing & Making Music, and The Performing Arts*. The necessity to link education, therapy and leisure in a holistic way will be emphasised. We would like to take this opportunity to thank all those colleagues who sent in material and, to put our a plea for further help. We have received a considerable amount of information on all the areas apart from 'the visual arts'. Any information or contacts on innovatory work in the visual arts and profound disability would be most welcome. We are looking for examples of expressive art such as painting, ceramics, pottery, photography, film-making and ways and means of how these activities can be made accessible to people with pmlD and how they fit in to education, therapy and leisure. It is anticipated the pack will be ready to go to the publishers in a couple of months so this request is urgent!

### *Ageing Matters: Pathways for Older People with Learning Disability*

BILD, PAMIS and HARC have all worked together to produce this distance learning pack, which is aimed at front-line staff and also family carers. The focus of the pack is wider than pmlD but their needs and those of their families are fully considered in all the materials. There are three separate sections to the pack, Individual Study Units, Managers' Readers, and a Resources Pack. These have now been published and details are available from BILD, the publishers of the materials.

### *Euforpoly Project*

In this project PAMIS is working with seven other partners from European countries. They are, Belgium (two groups), France (two groups), Portugal, Spain and Switzerland. The aim of Euforpoly is to develop and share information and expertise on all aspects of training and pml. Exchanges take the form of meetings of both parents and professionals hosted by one of the partners and also regular emailings between the partners. PAMIS' ongoing programme of training workshops for is seen as central to our involvement in the Euforpoly Project. Each partner has two co-ordinators, one parent and one professional as well as a number of other participants. The PAMIS co-ordinators are Loretto Lambe and Kathleen Murray who writes about her involvement in this project in this issue of PMLD Link.

### *Information Resource*

In addition to the projects described above PAMIS provides information to both parents and professionals in response to enquiries. The development of an accessible information resource is on-going and is being build up in collaboration with parents. We produce a quarterly newsletter and from time to time organise seminars and conferences all focussed on pml and the family. For further information on any aspect of our work please contact us at:the address below

**Loretto Lambe**  
**Projects Director, PAMIS**

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Lambe, L. and Sebba, J. (1988) The development and evaluation of workshops for parents and carers of people with profound and multiple impairments. *European Journal Special Needs Education*, 3, 257-66.

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## *Working with PAMIS - A parent's perspective*

My son James, who is now 18 years old, has Angleman's syndrome. For a long time I thought he was unique, but now I know he is only very rare. He is a very special young man and I feel privileged to be his mother. As a trained Nursery Nurse, I entered motherhood full of confidence, only to find that life was not that simple, and my education was about to begin. I very quickly realised that my life was different to that of my friends. As they celebrated each happy milestone in their child's life, I kept quiet. How could they understand about a child who never slept, did not want to eat and could not walk or talk! Gradually I began to meet other families like my own. How good it was to talk to mothers like myself, knowing they understood my problems, as indeed they shared them. The support of these mums carried me through the next few years. We laughed together, cried together and learnt together. However, I had not at that stage found an organisation or support group that I could fully identify with, one that really met my needs.

### *My introduction to PAMIS*

When James was 16 years old, my community nurse suggested I might want to go along to a meeting being held in a local hotel. Something to do with practical workshops to help families caring for people with profound disabilities. After sixteen years of coping on my own, I was more than interested. This was my first introduction to PAMIS, and little did I know then quite what an effect PAMIS was to have on my life! The meeting went well, although I was immediately disappointed at the small number of parents in attendance. This was an opportunity for us and I was determined not to let it pass. I had a lot of questions to ask, and ask them I did, even though I was conscious that I seemed to be hearing an awful lot of my own voice. I was very pleased with the answers I received. Shortly after this, Professor James Hogg (Chair of PAMIS) invited me to join the management committee for their Highlands initiative. I was delighted to accept. From the very first meeting, I became aware of how much work goes into the setting up of a PAMIS workshop, and the standard of service they intended to deliver. PAMIS were here to help. I looked forward eagerly to our first Highland workshop. It came in the shape of Communication, Eating and Drinking, and as James has no speech whatsoever and is a difficult eater, I found it very helpful.

Every workshop I have been to has given me practical help and advice which has led to changes for the better for both James and myself, and has had a ripple effect in that I have passed on what I have learned to my family and extended family. The workshop information packs are excellent and I now refer to them as my 'Bibles'.

## *Meeting with other parents from Europe*

In July 1996 James Hogg invited me to Dundee to a HELIOS round-table conference. I was thrilled to be asked but unsure of what to expect. I need not have worried. It was an amazing experience and the first thing I learned is that language is no barrier when people have a common bond, in this instance the desire to improve the quality of lives of people with profound and multiple disabilities and the those who care for them. As we sat round the table and listened to what was said, I wanted to speak too. To see the recognition in other parents' faces as they identified with what was said helped me to overcome my nerves. By listening to each other and sharing experiences we could learn so much. The second major thing I learned was that in Scotland, thanks to PAMIS, we are so much better informed than parents in many other countries.

Not long after the HELIOS conference came yet another invitation from PAMIS, this one quite taking my breath away. Would I represent the Highland parents at Euforpoly '96 Oporto, one of just three parents from Scotland? I could not possibly refuse so after acquiring a passport, organising respite care for James and leaving lists of instructions for my husband and daughter, I was ready to pack my bags. Panic set in when James Hogg asked me to put my thoughts down on paper as to how PAMIS had an effect on my life as a parent, and would I talk about it at the conference? What I wanted to say was easy. I knew exactly how much PAMIS had helped me. Saying it in front of all these people was a different matter altogether! It turned out to be a very exciting experience. I could feel the support of the PAMIS group and of the European parents and, with the calming effect of Lucy Rennie (a member of our group who was chairing the session), to slow me down for the interpreters, it turned out to be a few minutes that will live with me forever.

## *Parents getting their voice heard*

The follow up to Euforpoly Oporto 1996 was Barcelona 1997 and again I was invited along. I was now seen as the parent co-ordinator of the PAMIS group and was delighted to strengthen my friendship with parents across Europe with whom I have so much in common. We are now working together with our partners in Euforpoly to write a Parents' Document, detailing parents' feelings and opinions, their wants and needs in caring for their pmlD children. It is hoped that this document will be a starting point for the professionals who will work with pmlD/polyhandicapped (the European term) people and their families. By consulting with other PAMIS parents in three areas - Tayside, Glasgow and Highland - I can give a good representation of Scottish feeling. Other Euforpoly parents will do the same in their own countries, and we will combine these reports to write a document common to the needs of parents across Europe. I am honoured to be a part of this.

The Euforpoly project will finish at the end of 1998. However, the friendships and networks will, I am sure, continue long after that and, we were discussing at our last co-ordinators' meeting plans for Euforpoly II. Whatever the outcome, we, the parents and professionals, will continue to work together to ensure that '*Polyhandicap*' is always on the agenda and that the parent/professional partnership is strengthened.

## *Benefits to me, my family and other parents*

My contact with PAMIS has continued. I have attended every workshop run in the Highlands, apart from Challenging Behaviour, which was not relevant to my needs. I did however get a great deal of information from the Challenging Behaviour pack. The Dental Care workshop specifically led to my son having dental treatment while under anaesthetic for another problem. All professionals involved thought it was an excellent idea and co-ordinated it between them. I would never have thought of it without the initiative from PAMIS

In the Highlands, our PAMIS Special Interest Group has been meeting to discuss the difficulties involved with transport to and from schools and day centres. We are also concerned about safety in transport, both personal and public transport. Our most recent workshop was on *Understanding and Managing Epilepsy* and for the first time I am able to speak knowledgeable about my son's epilepsy, or more correctly epilepsies, as I now know that he has two types of seizures, *Tonic-clonic* and *Simple-partial* seizures - something I would have been unable to identify correctly in the past. The Personal Epilepsy Information Card developed as part of the workshop now goes with James whenever he is away from home. We are all looking forward to our next workshop which will be on the subject of *Making and Enjoying Music*.

PAMIS has had a very profound effect on families like my own and hopefully will continue to do so for a long time to come.

*Kathleen Murray, Inverness*

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RNIB Sunshine House School Northwood has just launched a new video, "**Moving Forward**" which focuses on the lives of four pupils who attend the school.

Sunshine House School is for blind and partially sighted children aged 2-11 years. The children have a wide range of ability and all follow the National Curriculum at an appropriate level. Many of the children have additional disabilities, including physical and learning disabilities.

We see how every child at Sunshine House School is "**Moving Forward**" with their own individual educational and care programme which includes physiotherapy, speech therapy and hydrotherapy. We also see the children in their classrooms as well as at leisure and play.

If you would like to see a copy of "**Moving Forward**" it is available free on loan or may be purchased for £5. Please contact: Rita Kirkwood, Headteacher, RNIB Sunshine House School, Dene Road, Northwood, Middlesex, HA6 1DD, telephone 01923 822538.

# *Twins and the Family*

## **Introduction**

Throughout the world there is an upward trend in the rate of multiple births. This is especially true in countries where the treatment of infertility is available. There has been a dramatic rise in triplet and higher order births - in the UK the number of triplets has trebled in the last decade. Families with multiple births face very specific problems even if the resulting children do not suffer any neurological disability, and there is a growing awareness that many professionals have insufficient experience to provide the optimum care, support and advice to such families.

The parent-led organisation, TAMBA, has successfully provided a large measure of mutual support for parents and forms the umbrella organisation for local Twins Clubs. The Multiple Births Foundation (MBF) provides professional support aiming to inform professionals about the special requirements of multiple birth families through a comprehensive education programme, and to provide some direct services to families including specialist clinics and telephone consultations. Both organisations have also published a wide range of written information for parents and professionals. Their addresses are given at the end of this article.

My own interest in the special needs of families with twins began long before the birth of my own twin daughters in 1994. While working as a pre-school support teacher at the Ryegate Children's Centre in Sheffield, I became interested in the fact that I seemed to have a high number of twins in my caseload. These twins did not necessarily have profound multiple learning difficulties. Indeed, some of the children were merely being kept under review as their development was felt to be at risk due to their premature birth. However, there were several sets of twins in whom one or both of the twin siblings had a profound multiple learning difficulty, and it is the needs of these children and their families which I will explore further.

## **Case Histories**

I will briefly illustrate two families which whom I worked over a period of some years, several years ago. The names have been changed and the descriptions have been kept non-specific enough that I hope nobody will recognise the families described.

### *Adam and Tom*

Adam and Tom were identical twin boys both of whom had profound multiple learning difficulties. My involvement with this family started when the boys were approximately 10 months old and continued to school entry. The boys were indistinguishable one from the other unless they were lying next to each other, when one could be seen to have slightly less curly hair than the other. Their mother did not dress them the same, but because their looks and the pattern of their motor difficulties were so similar she made sure that those who were working with them knew that their identity could be ascertained by their shoes, having their initials on the soles. Neurologically, they seemed to be identical except for the fact that Adam suffered from epilepsy, whereas his brother did not. Tragically, when the boys were approximately three and a half years of age, Tom died unexpectedly in his sleep leaving Adam as the surviving twin.

Adam went on to attend the local school for children with severe learning difficulties where I believe he still continues to be educated. He remains reliant on full body support in his wheelchair and is reliant on adults for all of his daily needs. He is visually impaired, seeing only light and dark. He has limited use of his right arm which enables him to use a touch sensitive switch with some degree of consistency.

### *Rebecca and Jonathan*

Rebecca and Jonathan were approximately 18 months old when I first knew them and they were living in the care of their paternal grandmother because, for a variety of reasons, their parents were unable to care for them. Rebecca had profound multiple difficulties with cerebral palsy affecting all four of her limbs. She had very limited head control and it was unclear how much she could see or hear. Her brother Jonathan, however, was able bodied and had all the needs of a boisterous 18 month old. I was involved with Rebecca for a total of three and a half to four years until she was settled into school. My involvement with Jonathan at that time was really because he was living with his sister. Rebecca was a very passive child who nevertheless enjoyed rough and tumble play, including tickling and swinging. Her relationship with her brother was evident in that she would still to the sound of his voice and, at times, smile when he played with her. Jonathan was, without exception, gentle and caring towards his sister whom he referred to as "My Becky" from a very early age.

The brief case histories given above were chose because, I believe, they highlight a number of issues which have to be considered in relation to working with twins. As with all children, the range of disability which can affect twins is very wide, from slight to profound and from rare to very common. As we have seen above, both twins can be affected either to the same or to varying degrees, or just one can be affected leaving the able bodied sibling with a range of needs of his or her own. Whatever the nature or underlying cause of the disability, it nevertheless follows that it affects the whole family.

If there is a healthy twin, this often means that the problem with the affected twin is picked up sooner than it might otherwise have been. If only one twin is affected, the constant presence of a healthy sibling of exactly the same age can be a powerful and sometimes painful reminder of what might (or should) have been. Losing the health of a child is a form of bereavement. In families of twins, there may also be grief over the apparent loss of a twinship. Being a parent of twins is something which most people, especially mothers, feel immensely proud of. Some parents will go to great lengths in order to preserve the 'twinness' of their children, perhaps in dressing them in identical clothes, while some find it easier not to remind themselves or others of the twinship, finding inevitable comparisons between the two children too hard to bear. The anger and guilt felt by many parents of children with severe and a profound disability can be all the more intense in a family with twins. This can be made all the more so if the children were conceived as a result of fertility treatment. Occasionally, parents find it very difficult to accept that the healthy sibling is indeed OK and may in the early years spend more time than average attending doctors surgeries or health visitor clinics.

Caring for twins, particularly in the early years, is a very demanding task. Caring for a disabled youngster is also extremely demanding. Caring for a disabled twin or twins can at times become too much for even the most well organised parents to cope with. Relationships in the family can suffer if parents do not have enough time to spend with each other. Shortages of time, energy and often money can lead to severe restrictions in what a family can do together. Social isolation can result. Fathers with twins tend to become much more involved in their everyday care than fathers of single born babies. However, much of the help given to the family of a child with special needs is aimed at the affected children and their mother as primary carer. The fathers can become marginalised and such a father may come to feel resentful or even angry, cheated and overwhelmed if he has not had the opportunity to express his concerns to involved professionals.

Parents of twins often go to great lengths to be fair to both children. This is especially difficult if one is disabled since it inevitably takes more time to care for the affected twin. It is inevitable that the healthier of the two will get less attention, but parents must remember that the child will not see it that way. The healthier twin may indulge in attention seeking behaviour or, in extreme cases, there may be regression until the healthy twin's behaviour resembles that of the disabled twin. Later in childhood and even into adolescence and adulthood, the healthy twin may feel guilty not only for his or her own



health, but also for his or her twin's condition as if he or she was in some way responsible for it. The needs of the healthy twin must not be forgotten whenever one is involved in the care or education of a twin with a disability.

Finally, I believe it is very important not to forget that a small proportion of twins die, either as babies or in childhood, and that the death of a twin can create even greater difficulties within a family than when a single child loses its life. Parents may find it almost impossible to care for the surviving twin for some time after the death of the twin sibling. I knew one mother who was quite unable to wash her daughter's hair as the sight of her with wet hair was too painful a reminder of how much she looked like her dead sister. Twins are no more likely to die in later childhood than single children. When they do, however, it can be devastating for the surviving twin. The loss of any sibling can be deeply disturbing for the survivors, but the special relationship between twins makes for a very special and deep sense of loss. This is no less so when the twin who dies has profound multiple learning difficulty. Many parents find that they have ambivalent feelings towards the surviving child coming sometimes to idealise the dead twin. Many bereaved parents find it particularly comforting talking to others who have lost a twin and TAMBA have a special bereavement support group which has a network of contacts as well as newsletters. In addition to this, the Lone Twin Network can be an invaluable support to single surviving twins who may be left feeling somewhat incomplete by the loss of his or her twin.

I make no apologies for the somewhat negative tour de force of this article. Suffice to say that my reasons for drawing your attention to some of the more difficult aspects of parenting twins is that many people have not had the opportunity to consider the difficulties facing the parents of twins, let alone when one of them has PMLD. Please rest assured that, for the majority of families with twins, including those where one or both twins has PMLD, many of the issues raised above will not be of primary relevance. However, please bear them in mind should you find yourself working with or caring for a family with twins or a twin child or children, please remember that any of the above may be a part of their lives too. I would also like to mention that whenever I mention twins I am also referring to triplets and higher order births.

Suzie Mitchell, Chartered Psychologist

#### **Useful Addresses**

Twins and Multiple Births Association (TAMBA)  
P.O. Box 30, Little Sutton, South Wirral, L66 1TH  
Tel: 0151 348 0020

Multiple Births Foundation  
Queen Charlotte's and Chelsea Hospital, Goldhawk Road, London W6 0XG  
Tel: 0181 383 3519  
Fax: 0181 383 3041

#### **Further Reading**

Cooper, C. (1997) *Twins and Multiple Births: The Essential Parenting Guide from Pregnancy to Adulthood*. London: Vermilion

Friedrich, E. and Rowland, C. (1984) *The Twins Handbook From Pre-Birth to First School Days*. London: Robson Books

Ryan, E. (1995) *Twins, Triplets and More: Their Nature, Development and Care*. London: Multiple Births Foundation

Sandbank, A. (1988) *Twins in the Family*. London: Arrow Books

## *Personal Reflections*

Having read Barry Carpenter's article in the last issue on 'Is the Family in Focus?' and the invitation to readers to share useful approaches in working with families, I began thinking about the many families that I have met during my career.

Prior to starting work for Mencap in 1995 I was a teacher, for more years than I care to remember! I worked in mainstream, special schools, support services and was also fortunate enough to have enjoyed two secondments and a year in America on a teacher exchange scheme.

Like many of you, throughout this time I worked extensively with a great number of families, in a wide variety of different contexts.

As a probationary teacher in Bristol with a class of forty 5-6 year olds I got to know parents, bothers and sisters, one or two aunts and uncles and grandparents at the beginning and end of the day, at the school gates, open evenings and through the occasional letters. Home-school books and frequent use of the telephone were not then on my agenda. What I did learn however about working with the families of the children that I taught was that each, in their own way, wanted the best for their child. For some this meant an emphasis on academic success, for others it meant ensuring that their child was settled in the morning and was happy, and for a few the fact that their child didn't get into any trouble was an achievement.

Moving up to Manchester offered a new challenge - a temporary job in an inner city Catholic Infant School, which soon turned into 5 years. I have very vivid memories of some of the children and families I got to know during this time. There was a great sense of community surrounding the school, with the involvement of the nuns, parish priest and friends of the school. Out of school events were very popular and well supported.

It was at this time that I began to get interested in working with the children who seemed to struggle with some of their learning - these were children who I imagine would today fall within the first 3 stages of the Code of Practice. How should we be supporting such children to learn successfully? Working from where each individual child was at, building up their confidence and developing positive relationships with families appeared positive ways to start.

An incident springs to mind of a father who came into my class one Monday morning and shouted angrily across at me:

'Why did you tell our Michelle that she has to go to church on Sunday? How can I take her? I've got.....'

I was rather taken aback but suggested that perhaps we should talk about this with the headteacher. She dealt with the situation admirably and explained to the parent that I was not in fact a Catholic and was probably the last person to be putting pressure on his daughter to go to church! The point of the story? - the father was given the opportunity to talk and was offered some practical support in what was a very difficult time for him and his family. Children live in families.

A move to a school for children with a physical impairment meant that I got to know many more families and their children. These parents wanted the best for their children, wanted them to achieve, make friends etc. just as all the other parents I had met. They also experienced particular issues related to having a child with disabilities and to me the important factor was still to get to know the individuals concerned and find appropriate channels of communication. For some this did mean 'open access' - 'I have a problem and I need to talk about it now', others wanted support 'as and when', for others more formal opportunities sufficed. I learnt to listen, to respect each individual's point of view, to share experiences, to 'be there' at the difficult times and to celebrate the good times. I was the one who was learning.

My year in the States was something else! I moved from working with primary aged children and their families to working with the 'adolescent years', young people aged 12-16 years. At the beginning of the year I did wonder how anyone could work with this age group, yet by the end I was converted. Why? Again, because I got to know the individuals and their families and though the contexts were very different similar issues arose - about understanding, empathy, respect, listening, offering practical and emotional support when able to and celebrating positive achievements.

'Assertive Discipline' was in force throughout the school. "Negotiate a contract with each of your classes" my exchange teacher told me while sitting on the wall outside my house in South Manchester. Upon being asked to enlarge on this she talked about 'do's and 'don'ts, rewards and sanctions'. "Sanctions?" I asked, "give me one or two examples," which she dutifully did. There appeared to be a hierarchical order to the sanctions, culminating in a 'telephone call home to the student's parents'. "However you will never get to that stage," I was dutifully assured.

Three weeks into the Autumn Term (or should I say the First Semester) I found myself walking down the corridor of a Junior High School accompanied by a very angry 15 year old young lady muttering to herself, whilst I was panicking about 'where is there a phone we can use?'

Thank goodness for deputy headteachers. On walking into the General Office Mr L. summed up the situation and asked if I would like to use his office and could he please have a word with Sharon's mum when she had finished talking to her.

Later that year I introduced Sharon to my family when they visited - life was not always easy in class but I think we grew to respect each other and understood our own boundaries. I did not meet Sharon's mum very often but the school had built up a supportive relationship with her which I was able to build on. Working with families is also about working together as a school and developing mutually beneficial practices.

A year in the Support Services proved to be extremely interesting but I did miss the close contact with families, which was in my particular situation more transitory.

My last teaching job was as a deputy headteacher of an all age school for children with severe learning difficulties, where I worked for ten years with two spells as acting headteacher.

This was where I met many parents of children whom we describe as having PMLD. I also met aunts and uncles, brothers and sisters, close friends and neighbours, just as at the school I started teaching in. However I think it is true to say that I built up relationships over a longer period of time, for of course many of the children were at the school from an early age until they left..

I do feel very privileged to have been part of these families lives for a number of years. In my various roles as class teacher, support teacher, deputy headteacher and acting headteacher I, listened to parents, laughed with parents, cried with parents, talked with parents, offered information and advice as appropriate, wrote reports, organised reviews, attended parent meetings, showed new prospective parents around school, welcomed new parents, arranged training sessions and open days and evenings ..... I'm sure I contributed to keeping British Telecom in business and learnt the art of speed writing with the regular use of home school books and diaries. In some families parents were synonymous with grandparents or aunts and uncles, particularly when they were acting as the main carers of the children.

In his article Barry Carpenter highlighted the multiplicity of services with which families of children with PMLD often have to engage with. Practical issues like checking with parents before a review if there are other people that they would, or in some instances would not, like to be present and liaising with other agencies such as the Educational Psychology Service and Social Services can help to share rather than duplicate information. We worked very closely with therapists and health personnel.

We had some wonderful Christmas shows, in which all the children were able to take part. These were always very well supported by families and friends and provided a great way of involving everyone and generating a sense of our community and the positive things that can be achieved. 'It'll be alright on the night' was a frequent cry heard the week before we hit the bright lights.

There are numerous examples that I could describe related to my professional involvement as a teacher with the families of children with PMLD and others. However time and space does not permit this so I will conclude with my personal philosophy -listen to families, talk to each other, provide practical support and assistance when able to and above all enjoy and value their involvement in school life. There will be difficult times, 'hard to reach' families, differences of opinion etc but at the end of the day we go home to our lives and families live with their children.

Now that I work for Mencap I am meeting more families, including parents, carers, brothers and sisters who support children and adults with profound and multiple disabilities. One mum springs to mind whose daughter attends the local mainstream high school. I really value listening to and discussing with her what living an 'ordinary lifestyle' means and how this can be achieved.

Mencap was started over 50 years ago by the mother of a disabled child who invited other parents to contact her about the lack of educational opportunities for their children, following the 1944 Education Act which excluded children 'with an IQ of less than 50 from *normal education*'. The National Association of Parents of Backward

Children was formed, which by 1950 had launched a new magazine "Parents Voice" with the aim of keeping parents in touch and spreading information and positive action. From these small beginnings Mencap has grown to be the largest Voluntary Organisation for people with a learning disability and their families and carers. It provides a large range of services across the country, including housing, employment, leisure activities, advocacy schemes and a variety of other support services, including the provision of information and advice.

The accent is on enabling families and individuals with learning disabilities to lead positive lifestyles and campaigning to ensure that equality of opportunity really does mean that, with sufficient and effective resources in place to make it a reality.

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Optimum House, Clippers Quay, Salford Quays, Manchester M5 2XP  
Tel: 0161 888 1200  
Fax: 0161 888 1211

*National Year of Reading: Mencap Parents' Pack for  
Children and Adults with PMLD*

MENCAP has been awarded a £15,000 grant to produce a Parents' Pack for families of children and young adults with profound and multiple disabilities. This will form part of the National Year of Reading, a Government-backed campaign to promote reading throughout the nation, which will be launched in September, 1998.

The Project is expected to start with a research and development phase in June, 1998 and run until August 1999. During the Year the Project will run workshops for parents in Birmingham and Manchester and will produce a Pack, based on examples of good practice, which will be of lasting benefit beyond the National Year of Reading.

The Project will produce a multi-media pack for parents in how to promote and stimulate reading in its widest possible sense. MENCAP is keen to make sure that children and young adults with profound and multiple disabilities are included directly in activity throughout the National Year of Reading. A key component of the Pack will be promoting an understanding of story in all its forms and suggest ways in which parents can use story as a way of enabling their children to engage with and make sense of the world around them.

The purpose of the Pack and the workshops is to give very practical and sound ideas to parents and siblings on how to share stories with children with profound intellectual and multiple disabilities. The Pack and accompanying CD ROM are likely to include sections on the central importance of story; tactile books; multi-sensory books; ideas and stories by children for children; parents' own experiences on sharing books and stories; 'Talking Books'; 'reading walls' which tell a story in visual and tactile form (with ideas on how to 'do up' your child's bedroom!); the use of symbols as a bridge to textual literacy for some children; and a resources list.

The Project brings together a partnership with MENCAP as the project managers and workshop co-ordinators; Birmingham University's School of Education which will carry out research into good practice in the development of emerging literacy skills and provide a link with schools; Widgit Software Limited who will illustrate the use of symbols in literacy development; the RNIB's National Education Service; and the Royal Schools for the Deaf, Manchester.

The National Year of Reading is a key part of the Government's National Literacy Strategy and its policy to promote lifelong learning. The aim of the Year, which runs from September 1998 to August 1999, is to encourage both adults and children to read more, either for pleasure, work or information and, in particular, to encourage families to read together. Grants totalling £400,000 are currently being allocated to a wide range of projects around the United Kingdom. A further £350,000 will be available for Projects in this financial year.

Liz Attenborough, Project Director, National Year of Reading said: "This project is an excellent example of the very high standard of applications we have received for initiatives which will promote reading up and down the country. Reading - and not just reading books, but anything from newspapers to comics, magazines to CD ROM's - can help us all in so many ways. The National Year of Reading will be a fantastic opportunity for people from all walks of life to get involved and help get the nation reading."

For further information on this Project, please contact either:

John Lawton, National Education Officer (Adult Services)  
MENCAP 4 Swan Courtyard, Coventry Road, Birmingham B26 1BU  
Tel: 0121 707 7877  
Fax: 0121 707 6305

Maggie Morgan, National Officer (PIMD)  
MENCAP Optimum House, Clippers Quay, Salford Quays, Manchester M5  
2XP  
Tel: 0161 888 1200  
Fax: 0161 888 1211

## *Mencap's National Focus Group*

Mencap has recently set up a National Focus Group in support of individuals with profound intellectual and multiple disabilities (PIMD).

Many more children with profound and complex needs are surviving, entering our school system and moving on into adulthood. Mencap wishes to ensure that services and society itself can effectively manage the diverse range of needs presented by this group. Quality of life across all ages and disabilities will remain a fundamental human rights issue. Mencap realises the need to engage in a close dialogue with the major service providers of Education, Leisure, Health and Social Services in supporting and involving it's members.

The National Focus Group includes parent members as well as representatives from a variety of disciplines. It is co-ordinated by Maggie Morgan, Mencap's National Officer in support of people with profound and multiple disabilities and their families and carers and is chaired by Barry Carpenter, Chief Executive and Principal, Sunfield.

The National Focus Group will be organising three 'Seminar Days' per year with key speakers and round table discussions centring on pertinent issues relevant to people with profound and multiple disabilities and their families and carers. Other participants/contributors will be selectively invited to each day, according to the chosen topic.

Projected outcomes of the days include:

- a full exploration of the chosen topic, through discussion, questions, sharing information and problem solving
- agreed criteria/values and identification of areas of good practice, from both the child and adult perspective
- practical suggestions on implementing change
- identification of possible areas for future development/research
- an annotated bibliography on the theme
- information on relevant training courses/conferences
- a written summary, in the form of a Briefing Sheet, to be available for circulation both internally within Mencap and externally through a variety of networks.

The first seminar will be on 18 June 1998 and will be addressing 'Quality of Life' issues for individuals with profound and multiple disabilities and considering what is the proper role of services in relation to this. Further seminars are being planned on person centred planning and advocacy.

The National Focus Group would be interested in hearing of other key issues from people working in this field. These may form the focus of future seminars, hence generating Briefing Papers which could be widely disseminated. Correspondence should be addressed to:

Maggie Morgan  
Mencap National Officer - PIMD  
Tel: 0161 888 1200  
Fax: 0161 888 1211

Optimum House  
Clippers Quay  
Salford Quays  
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*Do you work with people who have a learning disability?  
Is it difficult to get useful information?  
Would families that you work with like to receive more information or support?  
If so, Mencap's Family Adviser Services could help.*

Fifty two years ago Mencap began as a group of parents campaigned together to get education for their children with learning disabilities. Over the years Mencap has helped families through Local Societies and through staff from the Royal Society; all aiming to give people practical support when they needed it. As the organisation approached its fiftieth anniversary a strategic review and independent research told Mencap that getting information was still one of the most difficult things for people with learning disabilities and their families. The Royal Society decided to establish, for the first time, services which dealt exclusively with giving information and supporting people whilst they used that information - to be called Family Adviser Services. A network of services across the UK were needed and the organisation launched the Blue Sky Appeal to help to fund the development and establishment of up to eighty services.

Family Adviser Services aim to provide enquirers with clear, accurate information and the opportunity for support as people decide what to do and how to use the information.

Each Family Adviser Service comprises of:

- A Family Adviser
- One or more teams of trained volunteers
- The Mencap National Information Service.

**What does the Family Adviser Service offer?**

The Family Adviser Service provides information and support to people with learning disabilities, their families and carers. Professionals working alongside people with learning disabilities also come to Family Adviser Services for information. Enquirers may have questions about benefits or a medical condition, may want to know about assessments, schools or leisure opportunities. Sometimes people just want someone to talk to and that is part of the Family Adviser Service too.

**The first contact with the Service is with the Family Adviser.**

The Family Adviser is a paid member of staff who is responsible for co-ordinating the service in a defined geographical area. They have an office base and secretarial support and they build up networks of contacts in their Service area. The volunteers are recruited, trained and supported by the Family Adviser. The Adviser is also responsible for searching within and adding local information to the Mencap National Information Service.



**Next the Family Adviser finds the information needed to deal with the enquiry.**

The answer may be straightforward but in many situations the enquirer needs a face to face meeting and some time to talk about the concern or question. At such a meeting the Family Adviser will consider, with the enquirer, whether a volunteer might be helpful to offer information and support throughout the time it takes to deal with the query.

### **Family Adviser Service Volunteers**

Volunteers come from all sections of the local community. The volunteers, some of whom have family members with a learning disability, are trained to provide information and support. They are able to listen to the enquirer and they understand the issues that affect people with learning disabilities and their families. The volunteer can share relevant information with the enquirer, help them to understand it and decide with them how best to proceed. They work alongside the enquirer until the problem or question is sorted out.

The Family Adviser organises the volunteer training. Mencap has developed a training course specially for these volunteers which ensures that they have the necessary skills and knowledge to work within the service. The course is externally accredited by the Open College Network.

### **The Mencap National Information Service.**

This computer based system manages local and national information about learning disability issues. This ranges from details of local resources and services, information about national organisations, summaries of legal and Government documents to useful lists of references and research items.

The Family Adviser uses the system to find the information needed for each enquiry. Pages from the Information Service can be printed and given to the enquirer.

*Mencap is developing a network of Family Adviser Services across the UK in conjunction with ENABLE (in Scotland). At present there are twenty one services in operation and six new ones should be in place from April 1998.*

*For more general information please contact:  
Mencap Public Liaison Unit on 0171 454 0454.*

*For detailed information about Family Adviser Services contact:  
Rachel Raymond, National Family Support Officer on 0121 707 7877.*

## ***FAMILY WORKSHOP DAY AT CHELTENHAM***

As part of Mencap's work with people with profound and multiple learning disabilities, a series of workshops for parents and carers were planned in the Western Division in Gloucestershire, Herefordshire and Worcestershire regions. The workshops were a joint initiative between the Family Adviser Service, Homes Foundation and the Worcester Day Project.

The workshop day in February was planned as a pilot project on a small scale in the hope that, if successful, similar workshops could be held elsewhere in the region. Feedback from parents to the Family Adviser service in Gloucestershire suggested that there was a need for information on Wills and Trusts. We therefore decided to run the pilot workshop on this theme. We also decided to hold the workshops on a Saturday so that carers who work would be more likely to be able to attend.

We felt it was important to make the event a day for the whole family and the day was structured as follows. In the morning there was a talk on Planning for the Future, with information on Wills and Trusts, by a local solicitor. The solicitor in question was well known to Mencap and a parent himself of someone with a learning disability.

This was followed by lunch with an opportunity for discussion among attendees. The lunch was provided by students with a learning disability from the local FE college and the money they made was going to be put towards their residential trip in the summer.

In the afternoon a session was run on stress management and relaxation techniques for carers, an opportunity to gain hands on experience with massage, breathing techniques and stretching. This session was provided by a local worker with experience in this field and we felt provided a tranquil afternoon after the serious nature of the mornings topic.

At the same time as these workshops, leisure sessions ran all day for young people and children with special needs and their siblings so that carers were free to enjoy the day. Activities included arts and crafts, cookery, adapted games and a disco. The disco was provided by people with a learning disability from a local Mencap home.

From a safety point of view we felt it was important to hold the leisure workshops at the same venue as the workshops for parents so that they were on hand if necessary. We were fortunate enough to be offered the Oakley Day Centre in Cheltenham free of charge. It proved an ideal venue with good facilities and plenty of room for the various leisure activities.

The publicity for the day proved a mammoth task. All the special schools in this half of the county were sent sufficient flyers for the children to take home. In addition to this a further 1300 mailings were sent to adult Opportunity Centres, clubs, societies, libraries etc. in the area and to all the families in contact with the Family Adviser Service.

The response to the day was huge, and we were fully booked well before the event. In fact, we have a waiting list of 30 families ready to attend the next workshop day. Over fifty parents and 22 young people attended on the day. We asked all participants to complete an evaluation form and the overwhelming view was that the day was excellent. Parents really appreciated the fact that their children and young people were able to attend the leisure workshops leaving them free to make the most of the sessions. Due to the success of the day we are hoping to run similar workshops on this and other topics elsewhere in the county.

Jo Sullivan  
Family Adviser, Gloucestershire  
Tel: 01242 254747

## Communication for All

Wealth in a country is not always synonymous with human rights. This is so in Luxembourg, where the need to promote access to quality education for adults and children with learning disabilities is of paramount importance.

Flo Longhorn, Principal Consultant in Special Education, and Catalyst Education Resources, Wootton, Bedfordshire, in association with the Centre for the Study of Special Education, Westminster College, Oxford, hosted a two-day conference and seminar programme at the European Parliament in Luxembourg under the patronage of Madame Marie-José Jacobs, Minister for Disabled Persons, Luxembourg.

The aim of the conference was to present a dynamic approach to communication for children and adults with special needs through touch, gesture, multisensory environments, art, information technology, signs, symbols and pictograms.

The papers on which talks given at the conference were based are available from the addresses given below:

- \* Keynote speech: 'The Whole Person: Who Are We Communicating With?'  
'Communicating Together: Families, Professionals and the Community'  
*Erica Brown, Senior Lecturer (CSSE) and Education Consultant*
- \* 'Early Interventions: Stimulating Early Communication'  
'Symbols and Signs: Bridges to Communication'  
*Barry Carpenter, Director (CSSE)*
- \* 'Accessible Information: Developing a Newspaper Project for People with Learning Disabilities'  
*Jo Egerton, Researcher (CSSE) and Barry Carpenter, Director (CSSE)*
- † Opening Address: 'Communicating with the Community'  
*Emile Eischen, President, Autisme Luxembourg a.s.b.l.*
- † 'Communicating Through Touch and Gesture'  
'Sounds, Images and Environments: Innovation Through Technology'  
'Splash: Communicating through Art'  
*Flo Longhorn, Principal Consultant in Special Education*
- † 'Pictograms: A Way to Communicate'  
*Romain Schoos, Association des Parents d'Enfants Mentalement Handicapés – Fondation APEMH*
- † 'Communicating through Emotions: A Teaching Approach'  
*Elizabeth Scott, Teacher and Parent, Autisme Luxembourg a.s.b.l.*
- 'Communication through Music and Sound: The Soundbeam'  
*Tim Swingler*

\* CSSE, Westminster College, Oxford OX2 9AT

† Catalyst Resources, Beatrix Cottage, 1a Potters Cross, Wootton, Beds. MK43 8JG

• c/o Soundbeam, Unit 3, Highbury Villas, Kingsdown, Bristol BS2 8BY

Proceeds went to Ward 'Femme Six' at the Hôpital Neuro-psychiatrique de l'Etat, Ettelbruck.

## FUTURE FOCUS - Equal Opportunities and Ethical Issues

I write this Future Focus with some trepidation and a sense of the challenging and sometimes painful issues involved. Ideas about how best to promote equal opportunities for, and ethical behaviour towards people with PMLD rest upon very basic beliefs about right and wrong. Views about what is moral vary from society to society and, of course, from individual to individual within the same society. Below I have indicated a few of the issues which are debated currently. Do write and share your thoughts with us about this important topic.

One institution relevant to ethics that is available for consultation is the law. The legal statues of a society are affected *by* the population's views about right and wrong, as well as having effects *upon* people's ideas about morality. However, the legal system at best provides only a framework and final arbiter. It may well not be geared to the needs of a minority group, like people with PMLD. Thus, individual care givers (both formal and informal) may be left with many dilemmas and tensions to negotiate. This is true of our current legal system, where legislation about consent by adults who are not competent to understand the issues involved is long overdue.

On the other hand, the developing awareness of equal opportunities issues in the UK has had some positive effects for service users with PMLD. By 'awareness of equal opportunities issues' I mean to indicate the attempt to promote social justice involved in recognising that 'treating everybody the same' does not give them all an equal chance in life, and that we need to adopt strategies to address this situation. Differences of gender, race, disability and sexual orientation mean that we do not operate on a level playing field. Service providers have gradually recognised the need to consider these aspects of service users' identity. Moreover, the enshrinement of legal rights, as regards race and gender in the 1970s and most recently the Disability Discrimination Act 1995, have probably raised awareness and affected opinion in a positive direction, as well as giving some limited measure of protection against the most blatant forms of discrimination.

Nevertheless, many questions remain unresolved as regards the rights of disabled people, and there is no real consensus in some areas. For example, techniques for screening pregnant mothers for infants with congenital impairments are now widely employed. However, these procedures are seen by some disabled people as indicating that society does not accept disabled people and would prefer to be without them. This debate is likely to become even more intense as the current emphasis in biomedical research on the genetic basis of diseases leads to the development of more means of intervention.

Another area of disagreement about the moral course of action appertaining to disabled children relates to how strenuously health professionals should strive to keep alive profoundly disabled infants. Anecdotal evidence suggests that there is considerable variation in practice between UK hospitals. The decision making involved in these sorts of situations is taken by parents in consultation with medics, but it would be naive to underestimate the power of the doctors who clarify the possible options.

Decision making by and with adults with PMLD is no less complex. Consider the following case study:

*An adult woman with PMLD who has no verbal communication and no family contact is rehoused into a small group home after many years in a long-stay hospital. She benefits from the increased community links this brings. However, her visits to cafes and other community venues are restricted because she has a physical condition which results in the regurgitation of small amounts of each meal. There is some evidence that the service user herself finds this distressing, as well as it being considered socially unacceptable by other people.*

*Medical advice is that an operation may cure this condition, but carries a fair degree of risk. Hands on care givers are in favour of the operation being carried out and argue that the service user is likely to feel this way. They argue that the service user's quality of life could be considerably improved. On the other hand, the condition itself poses no threat to life, and the care givers are not without a vested interest as the condition is unpleasant for them to deal with. What is the ethically sound course in this situation?*

In my view, independent advocacy would be helpful in this case. Moreover, if surgery is likely to be a desired course of action, advice about gaining consent to non-emergency treatment would require input from the legal profession. This example serves to highlight some of the issues which exist as regards equal opportunities for people with PMLD.

Workers need to be very clear about their value base, and take care not to impose on service users their personal prejudices. Sexual behaviour is a case in point, including sexually activity and orientation, as well as contraception and sterilisation. There is much variation in individual care givers' views about sexual morality. People with PMLD may be particularly vulnerable to any inconsistency between workers concerning what is acceptable behaviour. Debates about protection versus risk as regards sexual and other activities are also influenced by carers' value systems.

In striving for good practice, there is one further question which may tempt workers to provide services which are ethically dubious for people with PMLD. This relates to policies, both national and local which, in the name of 'efficiency' or 'best value', demand more for less. Although services need to be run with effective financial management, understaffing or poor staffing may lead to unacceptably low standards and, as a consequence, unnecessary and illegitimate risks to service users.

It is important that those caring for people with PMLD discuss and debate the challenges they face in promoting ethical behaviour and equal opportunities. Do write and share with readers your views about the best way forward, or outline dilemmas with which you have grappled.

Judith Cavet  
Principal Lecturer, Staffordshire University

# reviews reviews reviews reviews

The following new publications, all building upon the extensive Fulton catalogue of titles in the field of special education, have been received for review:

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## **Interaction in Action – reflections on the use of Intensive Interaction.**

Edited by Dave Hewett and Melanie Nind.

David Fulton Publishers.

Following the major impact of *Access to Communication*, Hewett and Nind have brought together over three hundred pages of commentary on Intensive Interaction in practice. There is plenty here to interest staff working with people with profound and multiple learning difficulties as well as carers, parents, students and researchers.

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## **Promoting Positive Behaviour.**

Tim O'Brien.

David Fulton Publishers.

Tim O'Brien was the recipient of the 1997/8 Fulton Fellowship in Special Education. This book, the result of O'Brien's research and practical experience of working with pupils with learning difficulties, takes a considered 'whole pupil' stance. There is as much here about patterns of learning and spiritual development as there is about 'behaviour management'.

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## **Pathways to Learning in Rett Syndrome.**

Jackie Lewis and Debbie Wilson.

David Fulton Publishers.

Written by two practitioners who are active within the Rett Syndrome Association (UK), this book gives an introduction to Rett Syndrome; considers the factors affecting learning; explores barriers to learning specific to Rett Syndrome; and discusses the implications for teachers.

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## **Controversial Issues in Special Education.**

Garry Hornby, Mary Atkinson and Jean Howard.

David Fulton Publishers.

This book sets out to investigate the validity of the claims made in certain controversial areas of special education. In this largely discursive work, there are sections on conductive education, autism, inclusion, facilitated communication and the use of coloured lenses and overlays.

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## **Making Dance Special.**

Melanie Peter.

David Fulton Publishers.

In the wake of *Art for All 1 and 2*, *Drama for All*, *Making Drama Special*, and *Music for All*, the prolific Melanie Peter offers this 'non-threatening approach to dance education for the most challenged teacher and pupil'. The very practical

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contents draw upon the work of Sherbourne and Laban and provide support for those planning in the context of National Curriculum requirements.

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## **Parent-Teacher Partnership – practical approaches to meet special educational needs.**

Mike Blamires, Chris Robertson and Joanna Blamires.

David Fulton Publishers.

In the popular A4 format *Resource Materials for Teachers* series, this book presents photocopiable pages which can be used as handouts and OHP aids in development workshops. Aimed at staff, parents and governors, the information presented here is supplemented with ideas for activities, lists of contact addresses and useful resources.

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## **Values into Practice in Special Education.**

Edited by Geoff Lindsay and David Thompson.

David Fulton Publishers.

In the wake of recent legislation and changes in practice, this book focuses on the values underpinning approaches to special educational needs. There are sections on advocacy, parents, inclusion, assessment, school management and policy making.

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## **RESOURCES**

### **VIDEO packs**

*Approaches to working with children with multiple disabilities and a visual impairment.* A new educational pack for staff who support this group of children. The pack covers articles, practical ideas, curriculum design, and includes a list of support organisations and further reading on the main issues. £29.95 per pack. Available from RNIB Customer Services: 0345 456457 Please quote code PR.10930

### *There's Never an End to Learning.*

A video from RNIB for learning support assistants working with children with multiple disabilities and a visual impairment. Price: 29.95 plus £3.50 p&p. Available from RNIB Book Sales Service, telephone: 0181 968 8600

### *Communication through active music* by Inger Rodbroe and Tony Heyes.

45 page book and video on using music for interaction and communication with adults with dual sensory impairments. Price £25.00 plus p&p  
Available from Simon Banks Tel: 01225 874460

### *"Never say never"* Sherborne Developmental Movement at Grimsbury Park School.

35 minute video with teaching notes which focuses on the philosophical underpinning of developmental movement. It shows groups of pupils/students between 4 to 19 years of age and with differing abilities during scheduled movement sessions.

Further information from Cyndi Hill Tel: 0117 937647

### ***Please .....***

*let us know if you have found any books, videos, equipment, playthings, leisure resources etc. which you think are particularly useful. Tell us about your favourite resources and how you use them, or any articles, books or videos which have changed your way of thinking or doing things.*

## COURSES AND CONFERENCES

### JUNE

- 2nd to 4th Widening Horizons  
Practical approaches to providing learning and leisure opportunities for adults with profound and multiple/severe learning disabilities. Three days of short workshops.  
Run by: Orchard Hill FE Centre  
Venue: Orchard Hill FE Centre, Carshalton  
Further details: Andrew Lindup  
Tel: 0181 770 8125
- 4th Inclusion and the bystander role: how children with profound and multiple disabilities can be involve in the whole school porcess  
Run by: RNIB  
Venue: Garrow House, London  
Further details: Sylvia Franklin-Kitchen  
0181 968 8600
- 4th to 5th An Introduction to Loss and Bereavement  
Issues around loos and bereavement within the lives of people with learning disabilities. Stages of the grief process and practical ways of providing support to service users.  
Run by: ROC training and Consultancy  
Venue: St. Albans, Herts.  
Further details: ROC training and consultancy  
Tel: 01923 663628
- 4th to 23r July Music and Communication - Music for Non-musicians  
Two day course (continued on 23rd July)  
Run by: RNIB Multiple Disability Services  
Venue York  
Further details: Simon Labatt (RNIB Music Officer)  
Tel: 0171 388 1266
- 9th Intention to communication  
A course for professionals working with children with additional disabilities.  
Run by: RNIB Education Centre  
Venue: Grosvenor House, Leeds  
Further details: RNIB Education Centre, North  
0113 274 8855
- 13th Sherborne Developmental Movement: Level 1  
Run by: Sherborne Foundation UD  
Venue: Grimsbury Park School, Bristol  
Further details: George Hill  
Tel: 0117 937 3647
- 23rd Water based activities for visually mpaired children with additional disabilities.  
Run by: RNIB  
Venue: Merseyside  
Further details: RNIB Education Centre, North  
Tel: 0113 274 8855
- 23rd Multisensory rooms: how special facilities are to be maintained in inclusive education  
Run by: RNIB  
Venue: London  
Further details: RNIB, London  
Tel: 0181 968 8600



## JULY

2nd Starting MOVE  
Two day training on the MOVE curriculum  
Run by: MOVE international  
Venue: Gorway Conference Centre, Walsall  
Further details: MOVE International  
Tel: 01902 323066

## SEPTEMBER

13th bild 1998 Annual Conference  
to This conference will look at issues of quality for both  
16th service users and providers.  
Venue: Cavendish Hotel, Eastbourne  
Further details: Liz Howells  
Tel: 01562 850251

## OCTOBER

13th Introduction to Intensive Interaction  
Run by: ROC training and consultancy  
Venue: St. Albans  
Further details: ROC training and consultancy  
Tel: 01923 663628

## EXHIBITIONS

### JUNE

23rd Naidex International Exhibition  
to Run by Naidex Care Management  
25th Venue: Earls Court 2, London  
Further Details: Reed Exhibitions  
Tel: 0181 910 7873

### JULY

7th RNIB Vision '98  
At Kensington Town Hall, London  
Seminars and workshops covering opportunities in education and employment.  
Includes a fun area for children.  
Further information from: Jennifer Makin  
Telephone 0171 388 1266

## ONGOING

**PLANET** Training Events and Exhibitions:  
23-25 June Earls Court, London  
9.-10 September Wembley, London  
18-20 September Olympia, London.  
Further information from Planet, Cambridge House, Cambridge Grove,  
London W6 0LE Tel: 0181 741 4119  
Fax: 0181 741 4505

## LONGER COURSES

TEAM WORKS - a course for Learning Support Assistants working with children with visual impairment and multiple disabilities in special schools. 6 Modules involving 1 day direct training, written materials, directed work based activities and assessment based on students' workbook.,  
Training can be carried out at RNIB Education Centres - Coventry, London, Leeds, Belfast, Edinburgh, Cardiff, or Worcester.  
Further details from: Sylvia Franklin-Kitchen  
Tel: 0181 968 8600