

**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*

First of all, thank you to everyone who made time to send an article for this issue. Clearly the suggested theme - inclusion - is not one which fired people to write as only one article on that subject was sent, from Frank Wise school describing their well established practice. However, there are interesting articles on a variety of other topics, including one which continues the advocacy theme of the last issue.

Our next topic is Literacy, Literature and Drama and all related activities. As usual it is introduced in Future Focus written this time by Penny Lacey who has been working with Mencap and other organisations to produce 'Reading for All', the pack for parents of children and young adults with PMLD (reviewed by Barry Carpenter in this issue). The word 'literacy' immediately brings school to mind and young children struggling to read their first books. However, it can be so much more than *learning* to read, as teachers in schools have found out when implementing the National Reading Strategy. As so often happens, these new and often unwelcome initiatives unleash a torrent of creative thinking and new approaches in practice which send ripples through and beyond the world of education. This has certainly happened in this case, and we do hope that those of you who enjoy using literature and drama - in whatever form - with adults or children, will write in and tell us about it, and encourage others to share the enjoyment that can come from using all the different forms of literature that are available.

If there is any topic that you would like to be aired and debated in future issues of PMLD-Link, please let us know. We would like it to be a forum in which readers can discuss and share ideas on the issues which concern and interest you. So - let us know what these are. Nevertheless, articles on any subject are welcome, including feedback on any courses or conferences you may have been to, or information about any useful resources you have come across recently.

## **BUSINESS MATTERS**

### ***Subscriptions***

This is the last issue of this subscription year, so it is now time for you to renew your subscription for 1999/2000. There is a separate form included with this issue which I hope will make it easier to remember to send your subscription.

### ***Articles***

Articles or any other material for the next issue should reach me by 14th January 2000. They can be sent through the post or by e-mail to the following addresses:

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## *Integration links at Frank Wise School*

Frank Wise School, Banbury is an Oxfordshire County Council School for pupils with severe learning difficulties aged 2-16. We serve a catchment area extending to approximately a 15 mile radius of Banbury, which crosses the county border and embraces part of South West Northamptonshire. A significant proportion of our pupils have profound and multiple learning difficulties and are fully integrated within the school, which groups strictly according to chronological age and to no other criteria.

For many years we have devoted a great deal of time and commitment to establishing and nurturing educational links with a wide range of schools within the Banbury area. As well as our class-based integration links we also welcome a significant number of work experience placements into our school throughout the year. Although there have been many changes, developments and new initiatives in our integration work over the years, the principle aims of this aspect of our work remain the same...

- to develop the role of the school as part of the total educational provision in Banbury and the surrounding area.
- to foster understanding and positive attitudes towards our pupils across the community
- to offer our pupils a varied learning environment and a different context for peer group learning.

At present, all classes at Frank Wise School have an educational integration link with a school in the local community. A total of seven mainstream schools are involved in this way and several of the links are two-way. No pupil is excluded and classes integrate with their mainstream partner school for at least one morning or one afternoon per week. Activities are carefully planned and National Curriculum based, with mixed groups of pupils working together with teachers, LSAs and voluntary helpers from both schools.

In addition to this, some pupils integrate with their class's link school for individual sessions, or integrate individually into another mainstream school.

Frank Wise School also has an integrated nursery provision at Grimsbury St. Leonard's School, with children moving there from our assessment nursery for the academic year preceding their fifth birthday.

We are extremely grateful to all our mainstream partner schools who devote such time and commitment to our integration schemes. The huge educational and social benefits derived by both groups of children, in the mainstream schools and at Frank Wise School, more than justify the time and commitment spent on planning and liaising by the very dedicated teachers involved and there are important additional benefits - the exchange of expertise, sharing of resources and deeper understanding of other sectors of education.

It goes without saying that our integration partnerships with local schools are most successful when there is a genuine commitment on the part of the staff most directly involved and on the part of the management of the mainstream school to making it work. The philosophy must be right - integration must be seen as an educational opportunity, not a patronising act of charity. Occasionally in the past where senior management in the mainstream school have passed on an obligation to staff to integrate with Frank Wise School or where teachers committed to the partnership have not been supported and

encouraged by their senior management, it has been more difficult to make integration arrangements work.

We have found that effective and regular communication between the staff of both schools is vitally important. Planning and teaching responsibility for integrated sessions should be equally shared and there should be an agreed curriculum focus which fits appropriately into the long term planning of both classes from both schools. Teachers from both schools should use their knowledge and expertise from their different sectors to its best effect.

As school timetables become more squeezed by the plethora of curriculum initiatives with which they are obliged to comply, integration should be seen as an opportunity to deliver some of this work in a slightly different way, rather than as an optional extra which does not relate to the rest of the school timetable and "takes up too much time". Our integration at Frank Wise School is most successful where mainstream schools have looked upon the weekly injection of extra expertise and pairs of hands from Frank Wise School as a welcome opportunity to teach important areas of the curriculum in smaller groups, rather than as an unwelcome distraction.

### **Integration with Greatworth Primary School**

There follows a more detailed description of just one of our integration links - with Greatworth School, a small village primary school just across the county border in Northamptonshire. This is our longest established integration scheme. Greatworth has approximately 120 pupils on roll and our Year 5/6 class from Frank Wise School join the parallel year 5/6 class every Tuesday morning and every Thursday afternoon.

Our work there has always been characterised by the ambitious, high profile projects in which the pupils become fully involved.

We either work in three groups on one common curriculum theme (if we are working towards an 'end product' like an exhibition or some kind of a performance) or we work on three different curriculum areas around which the groups rotate. We like to have a 'celebration' of our work in mind when we are working together and are often working towards an event of some kind to which parents can be invited. Some of these large scale projects in recent years have included ...

- performing a 'Beatlemania' concert following our joint residential trip to Liverpool, learning about the 60s as a History topic
- performing the science fiction musical 'Rebecca's World' at the local arts theatre
- performing a 'Maths Circus'
- constructing an enormous ceramic monument to our integration in the Greatworth School grounds
- working with a school in Bradford on an ambitious performing arts project, performed in Bradford and Banbury
- performing a version of 'The Lion, the Witch and the Wardrobe' using half size rod puppets.

All of our work together has a strong curricular purpose and all pupils from the Fourth Family Group at Frank Wise School and from years 5 and 6 at Greatworth School are fully involved.

**Ludlow residential trip**

**Ludlow residential trip  
'The stand off'**

Another recurring and successful feature of our integration with Greatworth School is our annual joint residential trip which again is planned with a strong curriculum theme. This lasts for one week every year and usually takes place at the end of the summer term. Themes and destinations in recent years have been

- 1995 Broadhaven, Wales: working on 'the Science of the Sea'.
- 1996 Ludlow: working on poetry and creative writing.
- 1997 Bradford: working on a performing arts project with an inner city school.
- 1998 Harlech: art, working with the local artistic community.

We have always found it to be very important that our integration link be celebrated with displays, in newsletters to parents and in the press to afford it a high profile within the work of both schools. Photographs and video footage can be used in both schools to celebrate success and good work with the pupils.

Another very important aspect of our work with Greatworth School in recent years has been our partnership in the area of school-based Initial Teacher Training. We have cooperated together to train two teachers under the Licensed Teacher Scheme and the Graduate Teacher Programme. This has been an extremely successful venture in which the student teachers concerned have been called upon to differentiate their teaching from pupils with PMLD working at the earliest communication levels at Frank Wise School to the most able pupils achieving at Level 5 of Key Stage 2 in the mainstream situation. These teachers are now ready for anything!

#### **Setting up an Integration Link - Some Useful Points**

1. The most important thing, right from the outset, is to establish that the integration link is to be *educational* (ie. not just social) and is to have a clear curriculum focus at all times.
2. Go slowly at first - perhaps organise an opportunity for the two teachers involved to visit each other's classes then make time available for them to get together and plan the introduction. (Try to do this during the school day, which, in our strange school culture, attributes to it an automatic status).

Initial contact between the two school classes should be particularly good fun - choose a curriculum area which is a favourite of both classes. Perhaps play 'getting to know you' drama games so that the pupils are introduced to each other in an interesting way which is non-patronising. Sessions to begin with should be quite short.

3. After the first few initial contact sessions, the mainstream pupils may have lots of questions about the special school (including PMLD) pupils. Perhaps the special school teacher could come in to the mainstream class at another time to answer those questions alongside the mainstream class teacher - constantly emphasising the similarities between the two groups of pupils rather than the differences.
4. When contact is firmly established, choose another curriculum area which fits appropriately into the long term planning of both classes from both schools. You can now establish some important principles as to how your integration is going to run ...
  - a) Planning is shared equally between the two teachers. They should have short (half hour) regular meetings and establish regular telephone contact. (Good communication is the key factor in making integration arrangements work).
  - b) Teaching is shared equally between the two teachers plus any support staff. Where our integration has been less successful in the past has been where the mainstream teacher has been planning everything and the Frank Wise School group have gone along to 'join in'. 2, 3 or 4 available adults means 2, 3 or 4 equal-sized integrated

groups. (In our experience, mainstream teachers really value the opportunity to work with a smaller group for a whole afternoon or morning a week).

- c) Wherever possible, each term or half term's work should have a tangible outcome which can be celebrated - a joint display, a performance to share, a video or portfolio of work etc. This 'outcome' should be publicised in both schools and among both parents groups to establish and maintain the profile of the integration arrangement in the wider school community.
- d) Plan early for the next academic year to establish the integration link as a feature of the timetabling and long term planning of both schools. Also if teachers are moving around, try to decide as early as possible who is going to take up the baton and make sure they are liaising with their partner teacher in the other school before the end of the summer term.
- e) Implicit within the commitment to making integration work should be the principle that the integration is going to happen whenever possible and that it is not going to be arbitrarily cancelled from week to week as a casualty of something which is considered 'more important'. This principle must be clearly established between the schools before integration arrangements are set up.

5. You find that, as the arrangements go on there are lots of spin-offs - eg. shared expertise and resources between the two schools, and little things start happening which indicate that things are going well. For instance, this year our Frank Wise School class were invited to be on Greatworth School's class photograph for their leavers.

6. When things are going really well you can start branching out - joint playschemes during summer (we help plan Greatworth's and some of our pupils attend), residential trips etc.

**Michael Thompson**  
**Frank Wise School, Hornbeam Close, Banbury**



**The Bradford Project (1997)**  
**Three-way Integration**

# The West Cheshire Project

Having read the article on advocacy for people with PMLD, I thought readers might be interested in the work taking place in West Cheshire with children and young people with multiple disabilities.

The West Cheshire Project was set up in April '97 to look at helping children and young people with profound learning disability and major communication difficulties have their wishes and feelings more fully taken into account when they have short breaks away from home. In order to achieve this, every young person referred to the project would have their own independent volunteer advocate, who would be recruited, trained and supported by the Project and who would offer a minimum of two years to the young person.

The Project came into being from a number of workers in different organisations wanting to really fulfil the requirements of the Children Act in ensuring that any decisions made about short term breaks were taken "having regard to the ascertainable wishes and feelings of the child concerned (considered in the light of his age and understanding.)"

The different organisations involved were the West Cheshire Social Services Fostering and Adoption team who are responsible for the provision of family based short breaks, ASC (which later became NYAS) who had the contract with Cheshire Social Services to provide independent advocacy to all children and young people in the county who received a service under the Children Act and Barnardo's, which had two projects in the area that supported families who had a disabled child.

Together Barnardo's and West Cheshire Social Services were encouraging young people's participation at meetings but there was an awareness that there was a long way to go to ensure genuine participation from those who were able to use language reasonably accurately. The situation for those who didn't use formal language or who used it only in an echolalic manner was far worse, with parents expected to represent their son or daughter's wishes as well as their own and often the views of other siblings in the family.

It was this group of children and young people who made greater use of short breaks and yet we had not yet developed the skills required to help them make their wishes and feelings known. In looking around to see if others had developed a model that could be used to further these children's participation, there seemed to be a lot of discussion but no actual work focused specifically on this group of children.

There were plenty of reasons given why a pilot project looking at this area should not go ahead, but they could be summarised thus:

- It was too difficult to learn how such children communicated and it would take too long to get even the smallest hint of a feeling
- The children would not have the life experience to make decisions and it would therefore be lip service participation
- Parents represented their children and they would not want an advocate taking over their role.

The Project started from the position that **all** children and young people communicate but it may take us time and effort to rise to the challenge they offer us in understanding that communication. It is quite possible that they have very little experience of making



decisions, but the Project was aiming to find out about individual choice that could be fed into the decision making process, not giving them the mechanism to make the decision. As for parents' thoughts on advocacy, we felt that most parents welcomed input that was focused on getting the best for their son or daughter. Independent advocacy was an addition to be fed into the decision making process, certainly not about 'taking over' a parent's role. It would be entirely independent and not influenced by resource or finance implications. Parents would be able to elect to have this service and there would obviously be a need for the service to explain itself to parents and be receptive to parents' concerns etc.

The Project was influenced in its conception by some research done by Minkes, Robinson and Weston at the Norah Fry Research Centre between '92 and '94 involving children with learning disabilities in an evaluation of the respite services offered. They stated that

*"The children who cannot understand the questions or respond to them as they currently stand are perhaps those most in need of the protection of their interests which consultation should offer. Their needs may sometimes have to be considered independently of those of their parents and families ...The challenge set by the Children Act lends itself most obviously to wider adoption of advocacy and befriending schemes which introduce an independent view based on close personal knowledge and thereby enhance the chances of children receiving the services they need and want."*

The three agencies being willing to move beyond discussion to considering a pilot project, ASC, on behalf of the group, applied for various grants and managed to obtain funding for one year for Department of Health under the Refocusing Children's Initiative. Clearly funding needed to be for a much longer time, but it was decided to go forward and hope to attract additional funding as the project progressed.

Two years down the line, how far has the Project managed to achieve its original aims? Firstly, that it is possible to find people who would like to be volunteer advocates and who show considerable commitment to the young people that they are linked with. It has taken at least six months of regular contact for relationships to begin to develop and these relationships are at different stages throughout the project. Without this relationship and a good knowledge of the young person's wishes and feelings in general, it is impossible to have any meaningful input into the decision making process.

Communication is an absolute essential and volunteer advocates are encouraged to keep records of what they observe in order to build up a picture of total communication. Regular supervision and support are another important feature when the supervisor's role is to help the volunteer advocate relook at the communication and check out if the same meanings still seem appropriate. Checking and rechecking are seen as very important since such children and young people can use similar communications to convey a variety of meanings. Parents and siblings' input is welcomed as it helps to build up an overall picture but the advocate must be certain that it is what is shown to him or her that is represented, not the parents' perspective of that communication.

The volunteer advocate will only attend a meeting to look at the child's short term breaks when s/he feels that they have established a relationship and can offer input directly from the child. Having recorded different observations, they are in a position to explain why they feel the child has particular wishes. This has proved useful especially where parents may be getting a different view from the child and both views need to be considered.

Have there been any difficulties between volunteer advocates and parents? No, although there have been differences of opinion. To date, all parents have been able to see that the volunteer advocates speak from the perspective of what they observe, and that they are there for the child or young person. Sometimes, parents have expressed a view that they would like an advocate too, and although they have a social worker from Barnardo's, that does not always fulfil their needs. The Project does have a complaints procedure and all

parents are able to contact the Project co-ordinator, which is important even though any disagreements to date have been able to be amicably resolved.

There has to be input into helping service providers become more receptive to the input from this group of children and young people. There needs to be acknowledgment that non verbal communication is as valid as speech and that the review process can be conducted as an ongoing process rather than seeing its focus on six monthly meetings. Creating a receptive climate takes time, but needs to be happening alongside providing volunteer advocates.

The Project has also been guided by principles adopted by ASIST, in their booklet 'Watching Brief' where they suggest that in situations where a person has not expressed an opinion, the advocate may use a framework such as the Eight Domains to a Quality Life to raise issues for consideration. It is essential that it is made clear that this is not the person's opinion but a way of drawing attention to various issues and rights. Within this project, the underlying principles are those of Children's Rights and the advocate would be quite clear in only using that framework if the child had not been able to express a viewpoint on the subject.

It has taken a long time for relationships to be built up and that has created dilemmas in attracting funding. It is an expensive project and is likely to remain so as the intensity of input required to find, train and support volunteer advocates is constant. This has implications for service providers as a financial commitment in this area is likely to be high and a constant cost; given the long term nature of such a project, it is very difficult to rely on attracting grants and charitable donations. Ideally funding would be independent of service providers so maybe central government has a role if there is a real wish for disabled children to have the same chance to influence the service they receive as their non disabled peers.

Has it enabled the young people's views to be heard? In one situation, there has been a difference having an advocate but in others, it is too soon to tell. Certainly, the young people seem to be developing good relationships with their advocates but that could be seen in a befriending scheme. The difference is on the focus in that an advocate's role is to build up the relationship in order to understand the child's communication and represent that, whereas a befriending scheme is to build up a relationship and offer friendship. Advocates are also expected to help the child practice making decisions and expressing choice, often at a very basic level so they gain some awareness of becoming empowered.

As a pilot project, it is a case of 'watch this space!' So far everything has been positive but it is early days. I would be pleased to hear from anyone who is attempting anything similar and I can be contacted at the address below.

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### **References**

Minkes, J., Robinson, C. and Weston, C. (1994) 'Consulting the Children: Interviews with children using residential respite care services' *Disability Society* Vol.9.1.1994

*Watchine Brief. Making advocacy a right, not a privilege.* Information Leaflet No. 16 from ASIST, Advocacy Services in Staffordshire, 37 Harthill Road, Stoke on Trent, Staffordshire ST4 7QT Tel. 01782 845584

## **Professionals Supporting Parents when The Unexpected Happens**

The birth of a child represents an important event for a family. For parents of disabled children the loss of a long awaited 'normal' baby represents the death of the parents' ideal of what the child was to be. Families face a huge challenge as they grapple with the shattering experience of how to cope with something which was unexpected and how to accept an event which is unacceptable. The grief which parents endure is long term and has both physical and emotional consequences. Psychologically they have to face the dilemma of having brought into the world something which they had not expected. They have lost their 'ideal' of a baby in which they had invested their hopes and their dreams.

Several authors write about the isolation which parents face as they struggle to come to terms with their shock (Hornby 1994). The task of coping is a process in which parents find themselves constantly adjusting to the new demands which their growing child makes. Murgatroyd and Woolfe (1993) refer to this process as 'recurrent' crisis. In addition to psychological and physical implications, parents of children with disabilities often experience extra financial burdens as they endeavour to sustain a quality of life for their child in physical, emotional and educational terms. These tasks of psychological, social and physical coping are not mastered overnight. Neither can other people act as sole advocates for parents - they have to be enabled to act as advocates for themselves. Teachers, support staff and other professionals can support families and empower them in the days and years which lie ahead.

Most parents who give birth to a child with a disability will experience grief and a period of adaption and adjustment. Feelings of overwhelming loss combined with disbelief and anger are common, together with searching for a 'better diagnosis' in which they can invest some hope for the future. This process represents a classic model of grief. Furthermore, parents of disabled children are often plunged into grief at each milestone and transition point in their child's life and there is no alternative but to reflect on what 'might have been'. These emotional responses are sometimes referred to as those of 'chronic sorrow'.

Research has provided some interesting insights into the pace at which mothers and fathers adapt to their child's disabilities. Studies reveal that the primary carer in most families with a disabled child is the mother. Not surprisingly these mothers are likely to exhibit higher levels of stress than the mothers of non disabled children (Campion 1991). Additionally, mothers take responsibility for the majority of domestic tasks in families where there is a disabled member. Authors such as Carpenter (1994) describe fathers' perceptions of themselves as 'the peripheral parent' and a high incidence of emotional and psychological problems compared with fathers of non disabled

children. The crucial time for these fathers adjusting to being a parent seems to be at the moment of diagnosis, with particular reference to the way in which the news is broken and the setting in which it takes place. Not surprisingly there are parallels here between responses to shocking news in other contexts.

Alistair, father of Stuart, now in his thirties, said:

*"At first we thought there had been a mistake. Then we kept asking ourselves whether it was our fault. In the end you realise you can not through life burying your head in the sand. Reality of that first shock has been renewed so many time as our son has grown up."*

### **Parents developing coping strategies**

Traditionally there has existed a tension between the strategies and the tactics adopted by parents and those preferred by professionals. But parents need to be encouraged and empowered to develop the coping strategies which are best for them. The challenge to professionals is in helping parents to develop those tactics which will enable the strategies to work. The fact that parents have lived with the diagnosis or prognosis for their child for a long time does not mean that their initial feelings of shock, grief and anxiety are healed. The memories which they have learnt about their child's disability will remain very real and very detailed. Most parents who display a calm and controlled exterior will be struggling with turmoil within. Rarely will they have 'totally come to terms' with their child's difficulties. Many will live their lives in the hope that the diagnosis was wrong and it may be that which sustains them.

Professionals who work with parents long after their child's diagnosis should not make assumptions that, because a family has been coping for some time, they are not in need of constant support. The coping strategies which families learn to adopt and the skills they acquire need to be acknowledged.

### **Many parents will need:**

- continued support in adjusting to their emotional and psychological reactions
- assistance in seeking professional support
- support in recouping their physical strength
- assistance in ensuring benefits and resources to meet their needs

Whilst emotional support is vital for parents, there is an increasing understanding of the importance of honest and accurate information at each stage of their child's life. This will include:

- information about their child's disability and help to understand this information

- information about the consequences of the disability for the child's short term and long term development and within the context of their family and life style
- information about how to meet parents of children with similar disabilities
- information about rights and benefits including medicine, education, respite care and financial support

## Siblings

With the exception of the mother or primary carer, siblings are likely to have more contact with the brother or sister with a disability than any other person. Gascoigne (1995) includes the needs and difficulties of siblings of children with disabilities in her discussion concerning what she terms day to day life with a special needs child. She acknowledges that where a family has a member with special needs, this effects all the family. Children are not immune from perceiving the anxieties and stress which their parents are experiencing. Neither do they leave behind that awareness when they themselves go to school. Whilst it would be unwise to suggest that all siblings will themselves have special needs as the result of their family experience, teachers and professionals should be aware that children's academic performance, self esteem and social development may be effected. Feelings of rivalry and resentment exists between all siblings from time to time, but where a disabled child in a family is the focus of attention the feelings of other children can be overwhelming, combining jealousy, hatred and a sense of injustice. Stress seems to be more likely in the case of terminal illness or life-threatening conditions. Indeed it is not uncommon for children in the family to blame themselves for their brother or sister's ill health. Natasha, aged 13, told me:

*"It was probably my fault you see. I was the one who wanted to go to Disney World. It was when we were there that my brother got sick. If we hadn't gone we probably would have got help sooner."*

Another brother felt that his robust physique would have stood him in better stead during ill health than his tiny sister's frame. He said:

*"When the cancer gets really bad and she can't eat any more and she is too sick to keep the tubes in her, she probably wont last very long. I lifted her into her buggy the other day and she was no heavier than our spaniel dog."*

## What do siblings of brothers and sisters with disabilities need?

- Information to satisfy their curiosity
- Information to share with their peers
- Support, particularly if the disabled sibling has a genetic disorder
- Reassurance that they were in no way to blame for the disability
- To be involved in any long term discussions about the future of the disabled sibling
- Open and honest communication from their parents

- Opportunities to spend time alone with their parents.

### **Adapting to grief**

It is neither easy nor wise to attempt to delineate a time scale for parents or extended family members adapting to grief. The time involved will vary, but as with other major losses the process may take up to two years. Crucial to adaptation is the way in which professionals support families and allow them to come to terms with what has happened. Phases are not clearly defined and often parents speak of the confusion they experience as they struggle with a range of emotions.

### **The experiences of twelve families with a child with profound and multiple learning difficulties**

One way of obtaining information about how grief and disability effects families is to study how parents cope. I obtained information through a very small sample of twelve families where a child with profound and multiple learning difficulties had been born during the previous five years. All the children with disabilities had both parents living at home and either a brother or a sister in mainstream primary education.

I asked four categories of questions:

- Emotional responses at the time diagnosis
- Behavioural changes noticed in self or partner
- Changes in life style compared with before the birth of the child with disabilities
- Experiences of conflict within the family (including extended family) and in the local community.

The tables which follow outline the most commonly described changes in the families adapting to a child with profound and multiple learning difficulties. Most families will respond to the news of their child's disability with shock and then pass through a number of stages until they have achieved adaptation.

See Tables 1 and 2

At each stage in the adaptation process parents experience overwhelming emotional responses. These emotions will be experienced at different levels of intensity by different people.

### **Family Communication Systems**

Family communication patterns appear to be critical in determining how well families cope, since the most valuable sources of support are embedded in

Table 1

## Emotional Responses Experienced by Parents

Shock →	Denial →	Anger →	Sadness →	Detachment →	Reorganisation →	Adaption
↓ confusion ↓	↓ disbelief ↓	↓ blame ↓	↓ despair ↓	↓ empty ↓	↓ realism ↓	↓ reconciliation ↓
numbness ↓	protest ↓	guilt ↓	grief ↓	meaningless ↓	hope	coming to terms ↓
disorganisation ↓	disillusionment ↓		depression ↓	insignificance ↓		plans for the future
helplessness ↓	vulnerability		aloneness	inequality		
overwhelming loss						

Most parents will respond to the news of their child's disability with shock and then pass through a number of stages until they have achieved adaption. At each stage in the adaption process parents experience overwhelming emotional responses. These emotions will be experienced at different levels of intensity by different people.

(based on Brown, 1999, Loss Change and Grief - an educational perspective. London: Fulton)

Table 2

## Changes in Families Caring for a Child with Profound and Multiple Disabilities

<u>Emotional Responses</u>	<u>Behavioural Changes</u>	<u>Change in Lifestyle</u>	<u>Conflict within Family and Local Community</u>
<ul style="list-style-type: none"> <li>• Sad</li> <li>• Shocked</li> <li>• Scared</li> <li>• Unprepared</li> <li>• Angry</li> <li>• Disbelief</li> </ul>	<ul style="list-style-type: none"> <li>• Anxiety about own health</li> <li>• Sleep disturbance</li> <li>• Fear of developing illness</li> <li>• Inability to concentrate</li> <li>• Over dependency on employed work as an 'escape'</li> <li>• Eating disorders/alcohol or tobacco dependency</li> <li>• Over protectiveness of other siblings</li> <li>• Psychosomatic illness</li> <li>• Depression</li> </ul>	<ul style="list-style-type: none"> <li>• Changed emphasis on domestic activities</li> <li>• Decreased social opportunities</li> <li>• Increased dependence on extended family</li> <li>• Decreased time with family members living in the same household</li> <li>• Financial worries</li> <li>• Fewer holidays</li> <li>• Trying to provide stability for the future.</li> </ul>	<ul style="list-style-type: none"> <li>• Spouse or partner</li> <li>• Professionals</li> <li>• Other family members</li> <li>• Neighbours</li> <li>• Siblings school friends/peer group.</li> </ul>

(based on Brown, E., (1999). Loss, Change and Grief - an educational perspective, London: Fulton)



their relationships, open parenting styles, and philosophy. Evidence from a number of studies suggests that the families' cultural, social and educational background also influences how they cope. Furthermore the findings of Phillimore, Beattie and Townsend (1994) shows that economic status in families may be a factor in coping. My research suggests that families who were collectively able to communicate their feelings, facilitated adaption to disability more quickly. Children look to their families for support especially when situations are unknown and unexpected. Typically they mirror the coping strategies shown by their parents.

### **Caring for professionals who support families**

Many professionals suffer from personal stress as a result of their commitment to caring for somebody else. Several studies have focused on this experience (Lansdown and Goldman 1998, Brown 1993). Professionals working with families where there was child who was life threatened or life limited have cited the following factors as contributing to their stress:

- witnessing other people's pain and distress
- feeling unskilled in dealing with emotional responses
- physical exhaustion as a result of emotional trauma
- poor communication between themselves and families or other carers. (Brown 1999).

For families and children, the first two strategies adopted do not provide a solution. They highlight the fact there is frequently a tension between personal needs and professional expectations. In every human interaction there is a right distance which will be determined by the relationships. When we are working with families our relationships contribute to the well being of every family member but the balance between becoming over involved with people or professionally detached is a difficult one. The latter can lead to a lack of meaningful communication; the former to attachments which may be inappropriate and difficult to relinquish.

Caring for others is emotionally demanding, especially in the emotive environment of working with children with profound and multiple disabilities. We all bring our past experiences to the present. They are an intrinsic part of what shapes our humanity. As Simos (1979) so eloquently writes: 'Helping people to come to terms with the unexpected emerges from a compassion based on a recognition of the vulnerability of humans when they faced with loss.' It takes courage, determination and hard work to provide care which is worthy of being called excellent. Communities do not become successful places overnight. The challenge lies in the way in which people are prepared to become companions to families who live their lives with 'special' children.

### **References**

Brown, E., (1993). *The Experiences of Twelve Families with a Child with Profound and Multiple Learning Difficulties*. Oxford: CSSE, Westminster College, Oxford.

Brown, E., (1999). *Loss, Change and Grief - an educational perspective*. London: Fulton

Campion, J., (1991). *Counselling Children*. London: Whiting and Birch.

Carpenter, B., (1994). 'The Peripheral Parent: research issues and reflections on the role of fathers in early intervention'. *PMLD Link* (Summer), 19.

Gascoigne, E., (1995). *Working with Parents as Partners in SEN: Home and School - A Working Alliance*. London: Fulton.

Hornby, G., (1994). *Counselling in Child Disability*. London: Chapman and Hall.

Lansdown, R., and Goldman, A. (1998). 'The Psychological Care of Children with Malignant Disease'. *Journal of Child Psychology and Psychiatry*, 29 (5), 555 - 67.

Murgatroyde, S., and Woolfe, R., (1993). *Coping with crises: Understanding and Helping People in Need*. Buckingham: Open University.

Phillimore, P., Beattie, A., and Townsend, P., (1994). 'Widening Inequality in Northern England'. (1981 - 1991). *British Medical Journal*, 308, 1125 - 1128.

Simos, B.G., (1979). *A Time to Grieve*. New York: Family Services Association.

## Northam Lodge - A Parents' Initiative

In 1973 some parents of handicapped children, under the encouragement of a most caring social worker, formed themselves into a local association and, until 1977, provided a voluntary toddler group using the meagre but adequate resources on a four hours' a week basis of a social services day centre. The success of and need for this facility encouraged some parent members of the committee to plan longterm and, through active fund-raising - much easier in those days - in 1977 the property of Northam Lodge between Bideford and Northam was purchased.

Extensive modernisation and structural work was undertaken and, between 1979 and 1985 day activity groups took place for handicapped children and respite care was started, but unsuccessfully on account of the unpredictability of bookings.

In 1986 Northam Lodge welcomed its first six severely disabled residents for life, who were funded by social services. Close support from the ancillary health and social services was crucial and it is due to their early encouragement, which still continues, that Northam Lodge still prospers. ('For Life' means what it says - it is our intention to look after our residents through thick and thin and on the few occasions our residents have been in hospital, staff stay with them 24 hours, day and night.

In 1988 and 1989, following an approach from the Health Authority and with support from the Housing Association, Christopher and Gibson Lodges were built to accommodate local long stay 'patients' from the institutions.

Northam Lodge is now the permanent home of 21 severely and profoundly disabled residents whose ages range from 20 to 72. We have 60 staff, two thirds being full time. We enjoy close involvement with our residents' families.

### **The acquisition of Rose Hill**

In 1991 the Management Committee decided it would be beneficial to expand the social, educational and day care facilities of the charity and, through continuing fund-raising effort, purchased and adapted Rose Hill, a local Georgian property nearby. This characterful and listed property offers the ideal environment and ambiance to be a successful day care base for many of the Northam Lodge residents. The local FE college, North Devon, regularly uses Rose Hill as a partnership satellite training facility.

### **The ethos of Northam Lodge and Rose Hill**

Our residents are not ill, so we do not employ staff with a nursing background - no disrespect inferred, but this fundamental approach is crucially important. We look for positive well-being, excitement in life and appropriate stimulation as key ingredients. We want our residents to develop to their fullest potential and plenty of fresh air, a good healthy diet, a competent, experienced and well-trained staff who genuinely want to work with disabled people form the basis of our care strategy. We try to look after staff well and pride ourselves on a low turnover. We have an open style of management with an effective hierarchy system.

We believe strongly in the rights of each resident and that we should provide a opportunities to achieve a high quality of life and welfare harnessing their abilities and interests. For our profoundly disabled residents at Northam Lodge physiotherapy can be made to be fun, the Snoezelen and jacuzzi have their place,

music is important, intensive interaction under the auspices of the speech and communication specialist is crucial and rewarding, whilst trips out into the countryside with our vibrant and lively staff offer many dimensions of relaxation and therapy. We encourage our residents to have two holidays a year to benefit from the subtle dynamics of a short but busy break from the home environment.

Realistically the demands of business viability now predominate and the potential of Rose Hill, with its three acres of land, need to be better used. The charity is now planning additional to the day care mentioned above, for eight ambulant residents to live in the property from early 2000. It will certainly become a remarkable home for them.

### **Why?**

Rose Hill's ambiance generates an overwhelming atmosphere of relaxation and contentment and would have been a typical pretigious gentleman's residence of days gone by. It is spacious, solid and safe and its grounds offer exciting physical scope where horticultural and design projects will provide the main thrusts. North Devon's attractive and stimulating countryside offers much variety of which we regularly take advantage.

The aerial photograph shows Northam Lodge. In the top right corner is the buyngalow of Gibson Lodge and out of the pi8cture on lower right is the other bungalow of Christopher Lodge

**Michael Cope**  
**Northam Lodge**  
**Heywood Road**  
**Northam**  
**N. Devon EX39 3QB**

**Parent/Committee Member 1974-1989**  
**Development and Project Manager 1989-1997**  
**Manager from 1997**



## CHANGING PLACES - Accessible Loos for All



"Incontinence. Bladder. Bowels. Not a normal topic of social conversation. As a nation, I think we are obsessed with bowels, and whether they do or don't every day. Well, for nineteen years, I have had to live with not only my own bodily functions, but my son's as well. .... The bottom I gave birth to has changed immensely in that time, as has the size of the nappies."

These are the words of a mother of a young man with profound and multiple learning disabilities, describing just one part of her life looking after her much-loved son. As for other family carers in her situation, incontinence means a daily routine which involves quantities of adult-sized pads, extra baths, worn-out washing machines and lots of time. Without her vigilance, her son would be sore and smelly. She cannot be squeamish, and her son's personal privacy within the family has to take second place to dignity, hygiene and comfort.

Continence problems are a potential source of serious embarrassment to the individual and tend to remain a private anxiety and practical challenge. They are therefore not something the rest of the community tends to be aware of, including those who make policies and plan services. Our ignorance means that public toilets for people with disabilities very rarely meet the needs of older children or adults who need changing facilities. Their numbers may be far greater than is realised, and include not only those with profound and complex disabilities, but others with a range of medical problems and the frail elderly. After all, people in this situation tend to remain 'hidden' at home, because as a society we don't offer the resources to allow them to participate. Service providers are usually very aware these days of the need for mother and baby changing rooms, and also for toilets for those people with disabilities who can use a loo: however, it often comes as a surprise that these facilities do not meet everyone's needs.

Lack of good loos with changing facilities means that people with profound and multiple learning disabilities and their families miss out on opportunities to enjoy activities and facilities which others take for granted: for example, shopping trips, visits to the cinema, the park or the swimming pool. This is probably the most common and the most restrictive of the many barriers which deny them their right to full integration in the community.

A carer has to be both brave and physically strong to take their daughter or son with continence problems out and about, particularly if she or he is dependent on a wheelchair and adult. If a continence pad becomes soiled and no suitable changing facilities exist (which they rarely do) the options are to return home - or to lay out a towel or a coat on the toilet floor, lift the person out of the wheelchair and lie her or him down on it (if there is room). This is undignified, unsafe, cold and unhygienic for the person who is being changed. The lifting involved is also dangerous for both

people concerned. Then there is the pad to dispose of, and usually suitable bins are not provided. The whole procedure needs staunch commitment and a reliable sense of humour, and in many circumstances may be physically impossible. The alternative is discomfort and loss of dignity. It is therefore not too surprising that many families opt to stay at home if no changing facilities are available.

### **The 'Changing Places' Campaign**

PAMIS, a voluntary organisation working with families who care for people with profound and multiple learning disability, is launching a campaign to ensure that 'toilets for the disabled' become fully accessible for all. To meet the needs of those with continence problems and their carers, a loo should provide:

- a height-adjustable changing bench
- sufficient space for non-standard wheelchairs and also for helpers
- suitable disposal facilities

The 'Changing Places' Campaign is supported by a significant number of organisations working in the field of disability throughout the UK. They include the British Institute for Learning Disabilities, the British Toilet Association, the Carers National Association, the Spinal Injuries Association and Disability Scotland. A campaign pack is available from PAMIS, which includes a factsheet giving further details and a suggested layout, drawn up on the advice of physiotherapists and occupational therapists.

PAMIS would also very much like to receive information about examples of good practice in loo provision to meet these requirements.

If you would like a pack or to join the campaign, please contact:

*Jessie Roberts, Project Co-ordinator, PAMIS, White Top Research Unit, Frankland Building,  
University of Dundee DD1 4HN Tel: 01382 34 51 54 Fax: 01382 22 74 64  
e-mail [j.e.roberts@dundee.ac.uk](mailto:j.e.roberts@dundee.ac.uk)*

*PAMIS is a registered charity, No. 1011895*

A version of this article appears in the first issue of the British Toilet Association newsletter.

# Enhancing Quality of Life

## a project to develop transitional programmes for people with profound and complex learning difficulties

jointly managed by SKILL, the National Bureau for Students with Disabilities,  
and the University of Cambridge School of Education  
and financed by the National Lottery Fund

### Introduction

Students with profound and complex learning difficulties are under-represented in further education (FEFC, 1996) yet there is evidence to suggest that locally planned and co-ordinated provision offering an holistic response to the needs of these learners could significantly improve their quality of life (Hirst and Baldwin, 1994). This project, which is being funded by the charities board of the National Lottery Fund and jointly directed by SKILL, the National Bureau for Students with Disabilities, and the University of Cambridge School of Education, sets out to create a far greater understanding of the characteristics of such provision and, in particular, focuses on supporting the process of transition into adulthood (Griffiths, 1994) for people with profound and complex learning difficulties. The following notes give a brief introduction to the project. If you wish to comment on these notes; find out more about the project; or remain in regular contact as the project moves forward, please contact:

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### The project aims

Post-school educational options for young people with profound and complex learning difficulties are limited and provision is currently inconsistent. Most of the development work which has taken place concerns the education of school-age learners. With certain exceptions (FEU/MENCAP, undated; Nind and Hewett, 1994), models which do seek to inform education for students in the post-school sector are difficult to apply to young people with profound and complex learning difficulties. The aims of this project are therefore:

- to use existing curriculum models, research and an analysis of exemplary practice in order to develop a curriculum framework which will:
  - ensure that the wishes of the young person remain central during their transition to adulthood;
  - include innovative teaching strategies;
  - explore the potential of information learning technology;

- reconceptualise the notion of educational progress;
- devise appropriate forms of assessment and record keeping;
- examine ways of organising and utilising the learning environment;
- to reconceptualise the notions of advocacy and self-advocacy by:
  - analysing and classifying different forms of advocacy;
  - using research methods that ensure that the young person is seen as a partner in the research process;
  - devising guidelines for practitioners;
- to describe the organisational elements of an inclusive learning environment through:
  - identifying the structural and staff development implications;
  - producing guidance on policy, organisational and resourcing implications;
  - exemplifying ways of analysing local environments in terms of their potential for inclusivity;
- to develop approaches to inter-agency staff development which:
  - utilise methods of working that involve professionals in reflecting on, analysing and improving their own practice;
  - raise their expectations of learners' achievements.

### **The project outcomes**

There is a need to drive forward both policy making and practice in relation to post-school provision for young people with profound and complex learning difficulties. The project will therefore have two major outcomes:

1. A report which draws together the main findings of the project and defines an underpinning theoretical framework. This report will include:
  - concise recommendations (for bodies such as the DfEE, FEFC and DHSS) in support of policy development;
  - recommendations for the newly formed Regional Development Agencies on the potential for inter-agency working and the development of local collaborative initiatives;
  - a summary of the organisational, structural and staff development implications of establishing programmes with this group of young people, with guidance on implementation for managers of institutions and heads of service provision.
2. A multi-modal package of materials to support practitioners. This will include a copy of the report and guidance on:
  - curriculum development and delivery including:
    - what counts as progress;
    - teaching and learning processes and strategies;
    - the organisation of time and resources;
    - the management of the learning environment;
    - assessment and record keeping;



- inter-agency collaboration including:
  - criteria for allocating roles and responsibilities;
  - approaches to communication and information sharing;
  - establishing partnerships in practice between professionals, parents, enablers and young people themselves;
- promoting and working with a range of forms of advocacy, including:
  - individual self-advocates;
  - group advocacy;
  - supported advocacy through parents, enablers, professionals, citizens and named persons;
  - advocacy through voluntary bodies and lobby groups;
- analysing opportunities for and obstacles to inclusion in the local environment including:
  - existing provision;
  - practical access to facilities;
  - the skills and approaches of professions, enablers and members of the community.

The format of these materials would encompass a range of materials to support staff development and the creation of innovative practice and would include: text, video, audio-tape, ICT, OHPs, exemplar planning and recording formats, practical teaching materials, examples of best practice.

### **The project methods**

A range of methods are to be used in this project which will run from September 1999 until August 2002. The project will be divided into four phases.

In the first phase, running from September 1999 until April 2000, the project will use two approaches to gathering background information. Firstly, project officers will undertake a search of the current literature in order to inform the analysis of current provision and the methods to be used in this project. This work will produce an extended critical review of international research and an annotated bibliography.

Secondly, project officers will establish a database of existing post-school provision for students with profound and complex learning difficulties. Existing databases on transition, such as that held by the Council for Disabled Children, will be searched. A questionnaire, which is to be sent to all providers including schools, colleges and voluntary organisations, will then be designed and administered and the data analysed.

Using the results of the literature search and the questionnaire data, the project officers will undertake follow-up semi-structured interviews in order to identify four case study providers of innovative practice willing to participate in the later stages of the project in more depth. Case study provision may not be college-based but a local further education college should be willing to be involved and to explore the development of a future role.

In the second phase of the project, running from April 2000 until August 2001, the project officers will work directly with the four case study examples of provision. This in-depth analysis of practice will involve adopting an action research approach and working with staff from a range of disciplines as well as with managers, small groups of three or four young people with profound and complex learning difficulties and, where relevant, their advocates or significant others such as parents or key workers and parents/enablers. Strategies used during this phase will include:

- regular meetings between case study providers;
- analysis of and reflection on practice;
- critical friendships and peer observations between staff;
- interviews with parents and key workers to determine aspirations and support needs;
- the active participation of young people themselves and, where appropriate, their advocates, key workers or enablers.

The research officers will encourage reflective and collaborative processes in relation to practice and identify theory as it emerges. Teaching models, approaches, resources and materials will be systematically reviewed, redesigned, put into practice and evaluated throughout this phase of the project using an ongoing problem-based methodology. Project personnel will then begin to collate early drafts and versions of materials in order to prepare for further trials and evaluation during the latter part of the second phase of the project.

The third phase of the project will run from March 2001, overlapping with the second phase by six months, until December 2001. During this period, discussions and consultations with service managers will be held in order to identify the policy, organisational and resource implications of the emerging project proposals. The project officers will then begin the preparation of the various components of the final publications and materials. These will be presented to groups of strategic managers and practitioners through a series of regional seminars. The publications and materials will, in this way, be subjected to examination and evaluation before being finally prepared for publication.

The fourth phase of the project, running from December 2001 until August 2002, will be devoted to dissemination. Skill and the University of Cambridge School of Education will seek the support of the Further Education Development Agency (FEDA) in providing:

- a national launch, with invitations sent to a wide range of delegates;
- a series of local initiatives to ensure that the findings have a real impact in improving the delivery of services and, hence, the quality of life of young people with profound and complex learning difficulties.

A group of between twenty and thirty organisations across England and Wales, with an even spread of involvement across geographical regions, will be identified to take part in this final phase of the project. These organisations will receive the full set of materials and will be offered a systematic programme of support which will encompass:

- the development of organisational capacity in order to enable providers to respond to individuals who had previously been excluded;
- professional development introducing the project outcomes to staff and enabling them to work with these ideas in the context of their own practice;
- the facilitation of interchange between participants enabling them to share ideas and learn from one another's experiences;

- regular feedback sessions enabling participants to reflect upon the successes and difficulties of particular initiatives.

Members of the project team will then prepare a final report on the implementation phase in order to identify key messages for future work.

### **Key issues for this project:**

Members of the *Enhancing Quality of Life* team are already aware that this project will raise a number of challenging and contentious issues. Included among these might be:

- arriving at an agreed working definition of profound and complex learning difficulties which will be acknowledged and understood by a range of professionals in a variety of settings without demeaning young people themselves;
- promoting practical responses to the principle of inclusion, in education and in the community, for young people with profound and complex learning difficulties;
- identifying appropriate parameters for holistic approaches while working within statutory and professional boundaries;
- establishing ways of facilitating inter-agency working, collaboration and meaningful partnerships between professionals, parents, volunteers and young people themselves;
- conceptualising a realistic time scale for the transition process, conventionally regarded as running between established chronological ages such as 16 to 19 or 14 to 21, but which, for some individuals, may require more flexible interpretations;
- defining quality of life for people with profound and complex learning difficulties and finding points of balance between professional or parental perspectives and the self-determination of young people themselves;
- locating and consolidating ways of involving students with profound and complex learning difficulties meaningfully in the project and in their own learning.

### **Project personnel**

The directors of the project are:

- Lesley Dee – lecturer in inclusive education at the University of Cambridge School of Education;
- Liz Maudslay – assistant director of SKILL, the National Bureau for Students with Disabilities.

The project officers will include:

- Richard Byers – course director to the Advanced Diploma in Educational Studies (severe learning difficulties) at the University of Cambridge School of Education;
- Lani Florian – research associate at the University of Cambridge School of Education and independent consultant in inclusive education.

## References

FEFC (Further Education Funding Council) (1996) *Inclusive Learning – report of the learning difficulties and/or disabilities committee*. London: HMSO.

FEU/MENCAP (undated) *Learning for Life*. London: FEU.

Griffiths, M. (1994) *Transition to Adulthood – the role of education for young people with severe learning difficulties*. London: David Fulton Publishers.

Hirst, M. and Baldwin, S. (1994) *Unequal Opportunities – growing up disabled*. London: HMSO.

Nind, M. and Hewett, D. (1994) *Access to Communication – developing the basics of communication with people with severe learning difficulties through Intensive Interaction*. London: David Fulton Publishers.

**Rosemary**  
 **school**

**Training Unit**

## SUPPORT STAFF TRAINING

**Specialist practical training for workers in the field of Severe and Profound & Multiple Learning Difficulties.**

A series of 6 three-day Courses over two years starting in March 2000 and covering the areas of - autism, challenging behaviour, communication problems, disability awareness, PMLD, multi-sensory impairment and PSHE (including sex education)

(NVQ status is being sought through North East London University)

Speakers to include - **Dr. Penny Lacey** and **Rita Jordan** from the School of Education, Birmingham University  
**Dr. Dawn Male** from the Institute of Education, London University  
**Trish Johnson** from CENMAC.

Course Dates: **PMLD** - 15th, 22nd and 29th March 2000

**Autism** - 14th, 21st and 28th June 2000

**Challenging Behaviour** - 15th, 22nd and 29th November 2000

(Other course dates to be notified)

**Price per 3 day course - £150**

Further details from **Chrissy Brown**, Course Secretary  
Rosemary School Training Unit, 15 Woodbridge Street, London EC1R 0LL  
Tel: 0171 253 6893 Fax: 0171 336 6046

# *report back ...*

## INFORMATION AND COMMUNICATION TECHNOLOGY AND MULTI-SENSORY-IMPAIRED CHILDREN

The Greater Manchester Regional Multi-Sensory-Impairment Consortium (GMAMSIC) in conjunction with SENSE held a very successful Networking Day on Saturday 19th June 1999 on the above topic. The day was designed to re-start the network of teachers in the area and to foster co-operation between staff in the local authorities as well as to share ideas and expertise. There were 85 delegates who included intervenors, support staff, classroom teachers, heads of service, co-ordinators, advisory teachers and speech and language therapists. The cost was a nominal one of £10.00.

Kay Wrench, a teacher with Oldham LEA's Service for Visual Impairment, gave a very stimulating key note speech, with the technology back-up provided by her colleague Roger Bates from Inclusive Technology.

Kay began by stressing the importance of finding things that children are able to respond to. A key aim in working with children with multi-sensory-impairment (MSI) is to create opportunities for communication and active learning. With appropriate input devices, many children can control equipment for themselves, helping them to understand that they can make things happen. Through this control comes increased opportunities to interact with others.

'Entitlement' is a buzzword that is used frequently today. Kay pointed out that children also have an entitlement to TIME. Many children with multi-sensory-impairment may take longer to process information as well as using particular devices. Technology should not be used in isolation but as a carefully considered part of the child's learning programme.

Kay talked about the environmental considerations which facilitate learning for children with complex needs. It should be common practice to have computer systems mounted on adjustable trolleys, which can help to position the screen and any input device to suit each child. Other factors mentioned included the need for appropriate and comfortable seating and positioning, considering auditory distractions in the room and using good quality external speakers and headphones if needed.

Different devices can be used to access the computer depending on both the cognitive and physical ability of the child. Kay discussed touch screens, overlay keyboards, switches and switch progression.

As well as describing how technology can be used to support the development of communication, control and interaction, Kay highlighted the use of appropriate software to develop specific skills required by sensory impaired children. By carefully observing children using different types of software it is possible to obtain information about how they use their functional vision and hearing.

In conclusion Kay emphasised the fact that technology has much to offer children with complex needs as it is flexible and allows activities to be repeated again and again. Children are able to demonstrate abilities which cannot be shown in any other way. Training of staff is essential and used properly technology is a great motivator for both pupils and staff.

The keynote speech was followed by a choice of workshops, with participants being able to attend two of the following:

30 Ways to use a computer programme	Roger Bates, Information Director of Inclusive Technology
Sensory Stories	Linda Jones, Deputy Headteacher of Piper Hill High School, Manchester
Snoezlam or Bedlam! Using a multi-sensory room	Jenny Fletcher, SENSE West
Auditory Access: Practical applications	Patricia Gibbons, Advisory Teacher of multi-sensory impaired pupils in Manchester

A welcome addition to the day was Mr. Grumpy (Joe) from Grumpy House in Manchester. Delegates were able to browse through his bizarre array of stimulating materials salvaged from the waste bins and skips of businesses and services in and around Greater Manchester and take away many samples free of charge.

The Greater Manchester Consortium has been in existence for several years now and one of its main aims is to bring together professionals working in education who have an interest in children with MSI to share their ideas, information and expertise. In such a low incidence area it is particularly important for teachers, parents and support staff to work together. Children with PMLD have unique learning problems and a similar learning teaching style is often used to great benefit to develop interaction and communication.

GMAMSIC has a policy group, which meets regularly to develop policy statements and guidelines, which identify the educational entitlement and describe models of provision for children with MSI.

The Greater Manchester MSI Network meets twice a year regionally. For further details of membership (currently there is no charge) and events please contact:  
*Kay Wrench, Oldham Service for Visual Impairment, Park Dean School,  
St. Martin's Road, Fitton Hill, Oldham OLD8 2PY  
Tel: 0161 627 0443  
Fax: 0161 627 1147*

**Maggie Morgan**  
**Services for Inclusive Learning**

## **FUTURE FOCUS ..... Literacy and Drama**

The theme for the next issue of PMLD Link is literacy, literature and drama. The National Literacy Strategy has been around for a while now and we are sure there are lots of exciting activities going on in schools that would be good to share. What are you doing in the Literacy Hour? What stories/ resources/ books have you found useful? How have teenagers been involved in the Strategy? How has ICT been used?

We'd also like to hear from people working with adults with PMLD. Have you done anything special during the Year of Reading? Generally, what are you doing in terms of literacy? Are you involved in community activities? What have colleges been doing? Has anyone been involved in drama or a theatre group? Have you been to any PMLD friendly story or drama events?

As one of the projects for the Year of Reading, Mencap (with Royal School for the Deaf, University of Birmingham, RNIB) have put together pack for parents and families of people with PMLD. The material was gathered from schools and from parents. We are sure there are many more parents who have ideas for literacy activities that they could share with others through PMLD-Link. So come, all you parents, write something for this next issue!

Remember:

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

(Mencap, 1999)

Some people are sceptical about the value of literacy activities for people with PMLD but so much fun can be had from a shared experience round a story, especially if there are lots of things to look at, listen to, feel and smell; elements of routine as well as elements of surprise; and activities that can engage the emotions. Any book or story that you have enjoyed could potentially be suitable for adapting for sharing with someone with PMLD: Dickens, Shakespeare, Sherlock Holmes and Gulliver's Travels - the lot!

So please let us have your experiences and your ideas to share with others. Don't think that your idea is too paltry - send it in.

***Penny Lacey***  
***School of Education, University of Birmingham***

### **References**

Reading for All: Ideas for stories and reading for children and young adults with severe and profound learning disabilities. Mencap 1999

## reviews *reviews*

*Reading for All: ideas for stories and reading for children and young adults with severe and profound learning disabilities*

London: MENCAP 1999  
Price £20.00

In a National Year of Reading it would be easy to overlook the literacy needs of children and young adults with severe and profound disabilities, which is why this publication, directed solely on this group of learners, is particularly welcome.

This literacy resource pack is also unique in two other ways. Firstly, it is an excellent example of collaboration between organisations; (in this case Mencap, the University of Birmingham, the Royal School for the Deaf, Manchester, the Royal National Institute for the Blind and Widgit Software Ltd.). Their partnership has produced something truly worthwhile.

Secondly, the pack is written primarily for families of children and young people with PMLD. Any parent knows the value of sharing a book with their child, not only for its contribution to their literacy and language development, but also for the turn-taking and bonding that can take place at this special time. Families of those with profound disabilities often miss out on this experience, and yet the nurturing and social value for these children is even more significant.

The pack is presented in eleven easy-to-access sections. Much of what is contained will not only be of great help to families of children with PMLD, who have received little guidance in this area, but also to teachers and therapists. So much of what is described in the pack would be invaluable in the classroom for implementing the National Literacy Strategy. For those working in the post-school sector the resource suggestions are equally applicable, and clearly demonstrate how reading for pleasure should continue as part of a leisure or educational programme.

## reviews *reviews*

The sections on 'Using Books' and 'Adapting Classics' offer many useful story themes from schools themselves, and from skilled story-developers such as Chris Fuller (of Bag Books) and Nicola Grove. These are photocopiable and could be circulated around staff teams.

The pack is not without its theoretical framework too. The particular needs of this group of learners are considered, i.e. where there are additional sensory difficulties. Concepts crucial to the implementation of these stories, such as objects of reference, symbols, and sensory environments are also clearly explained.

This is both a timely and invaluable resource, and there are clear plans to take it a stage further through CD-ROM. The many and various contributors are to be congratulated on their initiative which will undoubtedly do much to enhance the quality of literacy learning for children and young adults with severe and profound learning disabilities.

Professor Barry Carpenter  
Chief Executive, Sunfield

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### *Interaction in Action*

Hewett, D. and Nind, M. (Eds)  
David Fulton 1998 312 pp £18.00  
ISBN 1-85346-461-9

This book offers the reader an opportunity to consider the use of Intensive Interaction in a wide range of practical environments. The original thinking behind this technique was described in *Access to Communication* (Nind and Hewett 1994). For those readers not accustomed to this (caregiver-infant interaction) model, some time is spent in the introduction familiarising the reader with the main principles of Intensive Interaction.

The fourteen well written chapters look at the practical implementations of Intensive Interaction in a wide variety of environments: schools, FE Colleges, Social Service establishments, residential units, day



centres and in people's' own homes. They also highlight the benefit that use of this technique has on the communicative ability of the following client groups: multi-sensory impairment, profound and multiple learning disability, challenging behaviour and autism.

This book highlights use of the technique by a variety of staff and also describes its use by parents. The technique is described as being applicable for use by all staff/carers whether extrovert or introvert!

Some of the benefits of Intensive Interaction are identified:

It can provide a direction/ focus for working with traditionally 'difficult' client groups mentioned earlier.

It can enthuse staff who are becoming demotivated by service limitations and can increase the knowledge/skills of working with the above client groups.

It can help staff to 'look' at clients in a different light and to observe communicative behaviours not previously witnessed or to interpret 'old' behaviours differently and to see the communicative intent within them.

There is discussion also on some problematic areas such as the possible conflict that this technique may have with other approaches such as behaviourism and normalisation, and also the fears that staff/carers may express on indulging in activities requiring physical contact. The editors go to great lengths to discuss these concerns and to provide reassurance and guidelines for users of the technique.

The book is well worth the cost, and should be considered essential reading for everyone concerned with the development of people with a learning disability.

Anthony B. Chairi  
Community Nurse  
Learning Disability Centre, Milton Keynes

### *Implementing the Literacy Hour for Pupils with Learning Difficulties*

Berger, A, Henderson, J. and Morris, D.  
David Fulton, 1999 117 pp. £13.00  
ISBN 1-85346-615-8

This book is designed to help schools and individual teachers to adapt the aims and principles of the National Literacy Strategy to the needs of pupils with moderate/severe/profound/ learning difficulties or complex needs in either mainstream settings or special schools.

Overall the book is written in a readable style and the organisation of the materials is clear and easy to follow. It is divided into three sections - the first concentrating on the rationale and aims of adapting the National Literacy Strategy for pupils with learning difficulties. Part 2 gives guidance in formulating a policy; including the literacy action plan in the school development plan; and developing planning (long, medium and short term). Part 3 is a scheme of work which incorporates all the suggested learning objectives for the three strands (word, sentence and text level) from the National Literacy Framework for the Reception year and year 1, term 1. These objectives are differentiated and related to the QCA targets p1-8 so that planning and assessment are directly linked.

One of the major assets of the book is the simple practical framework provided. The range of work for the primary years has been allocated to five broad age bands (EY/Y1 & 2/ Y3 & 4/Y5 7 6/ Y7+). I personally find this a realistic way of giving older pupils with PMLD appropriate but meaningful access to a breadth of literacy sources which will tie in with other initiatives which may be running in parallel eg. ALL and ASDAN. The learning objectives are not age related and the format of the scheme of work will allow adaptation for all key stages. This will be particularly useful for pupils with PMLD who may be working on a narrow band of learning objectives throughout their school career.

The suggestions for activities and strategies incorporated in the scheme of work give plenty of scope for relating them to the age, ability range and personalities of the group.

The format and suggestions are comprehensive but not so prescriptive that individual teachers have no chance to use their initiative and creativity. On the other hand, some teachers, particularly those with little experience of working with pupils with PMLD, might welcome more help in adapting named texts to provide multi-sensory access.

I am sure that any school embarking on implementing the Literacy Hour would find this book invaluable and those, like myself, who have already developed their plans will find it useful in clarifying and refining their practice.

Gloria Pantling  
Senior Teacher/PMLD Co-ordinator  
Alderman Jackson School, Kin's Lynn

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*Sex in Context: A personal and social development programme for children and adults with profound and multiple impairments*

Downs, C. and Craft, A.  
Pavilion Publications, 1997  
Part I ISBN 1900 600 501 Price £95  
Part II ISBN 1900 600 552 Price: £75  
Handbook ISBN 1900 600 609  
Included with Part I but  
available separately for £25

This publication provides a framework of ideas for work with young people and adults with learning difficulties. The title provides a cue to particular emphasis of the material in that sexuality is dealt with within the context of daily life. Although it provides ideas for particular sessions which will develop sexual awareness in its broadest sense.

Essentially the text is in three sections. Two are contained in a ring binder and the third (the Handbook) in a separate spiral bound paperback.

Sections one and two in the ring binder deal with devising a programme and actually delivering the programme. It is acknowledged that programmes have to be devised to meet the particular needs of any given group of people. Section 1 provides

ideas for working with staff to create a programme. Section 2 contains suggested group sessions in specific detail. Section 3 in the spiral binder deals with institutional issues such as writing a policy and specific guidelines for a variety of relevant issues such as intimate personal care, masturbation, and who touches who. All issues which need to be discussed.

This publication is a useful tool which contains clearly presented material which can be used with staff, parents and carers. It is stimulating and yet firmly based upon sound practice. It makes a genuine contribution to the development of work around the delicate area of sexuality.

In using the material myself I have found it a sound base although I have modified some of the ideas to meet the particular needs of my situation, as one would expect to do with any material.

Sue Chesworth  
Belstead School, Ipswich

## RESOURCES

### NEW BOOKS

*Reading for All: ideas for stories and reading for children and young adults with severe and profound learning disabilities* published by Mencap 1999 This pack is reviewed in this issue.

*Implementing the Literacy Hour for Pupils with Learning Difficulties* by A. Berger, J. Henderson, and D. Morris. published by David Fulton 1999. This book is reviewed in this issue.

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

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

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

*Access to eye care for adults with learning difficulties*  
*Looking for eye problems in people with learning difficulties*  
*How to get the best out of sight testing of adults with learning disabilities and/or no obvious means of communication.* Three fact sheets giving detailed advice to help people with learning difficulties access eye care service

## COURSES AND CONFERENCES 1999/2000

### NOVEMBER

- 9th On Target!  
Observing, Assessing and Targeting Effective Environments of Learning for Pupils with Profound and Multiple Learning Difficulties - a one day seminar.  
Organised by: Catalyst Education Resources Ltd.  
Leader: Flo Longhorn  
Venue: Liverpool  
Further details: Catalyst Education Resources Ltd.  
Tel: 01234 764108
- 11th Literacy and numeracy for pupils with PMLD  
Realistic learning and teaching approaches - a one day seminar  
Organised by: Catalyst Education Resources Ltd.  
Venue: Central London  
Leader: Flo Longhorn  
Further details: Catalyst Education Resources Ltd.  
Tel: 01234 764108
- 11th Learning through Touch  
Helping children with visual impairments and multiple disabilities to access the curriculum through touch  
Venue: London  
Contact: Eye Contact  
0171 388 1266
- 11th Carenet UK Conference  
For staff working in residential care with deafblind, multi-sensory impaired, MDVI children and young adults.  
Venue: Sense West, Birmingham  
Further details: Jacqueline Bailey  
01743 872320

- 12th Multisensory Education for Learners with Special Needs  
A one day workshop for learning support assistants in sensory development and education.  
Organised by: Catalyst Education Resources Ltd.  
Venue: Central London  
Leader: Flo Longhorn  
Further details: Catalyst Education Resources Ltd.  
Tel: 01234 764108
- 13th Explorations in Sound and Movement  
for pupils/clients with Profound and Multiple Learning Difficulties  
Organised by: Special Music Courses  
Venue: Sherwood Methodist Church, Nottingham  
Leaders: Kate Baxter and Penny Rance  
Further details: Kate Baxter  
Tel: 0115 960 9528
- 23rd Visual stimulation and the use of sensory software  
Venue: London  
Contact: Eye Contact  
Tel: 0171 388 1266
- 23rd and 24th Cultural Issues in Sexuality Work with People with Learning Disabilities  
Organised by: Consent  
Venue: Harperbury, Herts  
Leader: Seema Malhotra  
Further details: Consent  
Tel: 01923 670804
- 25th and 26th Working with People with Profound and Complex Disabilities  
This course aims to increase the awareness and knowledge of what we can offer to improve the quality of life and identify areas in which people with profound learning disabilities can develop and progress their lives  
Organised by: roc  
Venue: to be confirmed  
Contact: roc  
Tel: 01923 663628

## DECEMBER

- 1st "Why Music matters"  
The value of music for children with visual impairment and or additional and complex needs  
Venue: Nottingham  
Contact: Eye Contact East  
Tel: 01203 369500
- 2nd Essential Healthcare for People with Learning Disabilities: service provision, medical education and research  
A one-day conference for all those involved in undergraduate, postgraduate and continuing education, health authorities and primary care groups. The aim of the conference is to highlight the need to include in medical training curriculum the basic requirements of the patients with learning disabilities and to focus on the delivery of healthcare in this area.  
Organised by: Royal Society of Medicine/Mencap  
Venue: Royal Society of Medicine, London  
Further details: Emma Bryce, RSM  
Fax: 0171 290 2977  
e-mail: emma.bryce@roysocmed.ac.uk

6th Communication masterclass for pupils with multiple disability and visual impairment  
Venue: Edinburgh  
Contact: Eye Contact: Scotland  
Tel: 0131 311 8512

9th and 10th Aromatherapy for People with Learning Disabilities  
History of aromatherapy, therapeutic properties of essential oils and practical exercises including massage.  
Organised by: roc  
Venue: to be confirmed  
Contact: roc  
Tel: 01923 663628

## 2000

### FEBRUARY

9th and 16th and 23rd Exploring Sexuality Issues for People with Profound Learning Disabilities Parts I, II and III  
Organised by: Consent  
Venue: Harperbury, Herts  
Leaders: Christine Paparestis and Steve Simmons  
Contact:f Consent  
Tel: 01923 670804

10th and 11th Stimulating the Senses  
The six senses and how they evolve. Participants will gain experience in creating sensory sessions for service users or children with learning disabilities.  
Organised by: roc  
Venue: to be confirmed  
Contact: roc  
Tel: 01923 663628

18th to 20th Another Trio of Opportunities  
Dance & Drama (over 18's)  
Musical Interaction  
Towards Numeracy (including PMLD)  
Organised by: Special Music Courses  
Venue: Great Hucklow, Derbyshire  
Further details: Kate Baxter  
Tel: 0115 9609528

### MARCH

14th Cultural Issues in Sexuality Work with People with Learning Disabilities  
Organised by: Consent  
Venue: Harperbury, Herts  
Leader: Seema Malhotra  
Further details: Consent  
Tel: 01923 670804/670793

16th Music and Communication  
A practical one day course for staff who have little or no experience in music making who wish to use music in day to day work as a means of improving communication for adult clients with a visual and learning disability, particularly those with little or no speech.  
Organised by: RNIB Multiple Disability Services  
Venue: Belper, Derbyshire  
Further details: Simon Labbett, RNIB  
Tel: 01423 880866

18th Strum as you Sing  
- on the autoharp and chromaharp. Playing success is guaranteed at this one day workshop! All levels welcome.  
Organised by: Special Music Courses  
Venue: Nottingham  
Leader: Tim Gauntley and his team from Toronto  
Further details: Kate Baxter  
Tel: 0115 960 9528

25th Arts 2000?- Where are the Arts now for children with special needs?  
This conference will address the question in a dynamic and practical way that will take Arts in the Curriculum forward for children with special educational needs.  
Organised by: Sunfield Professional Development Centre  
Venue: Sunfield Professional Development Centre  
Further details: Jackie Wadlow  
Tel: 01562 883183

## JUNE

23rd Meeting the Challenge: Challenging Behaviour and the Arts  
to Challenging Behaviour  
25th Workshops in: Arts Therapies  
Communication and interaction  
Relaxation and leisure  
Organised by: Special Music Courses  
Venue: Great Hucklow, Derbyshire  
Leader: Dave Hewett  
Further details: Kate Baxter  
Tel: 0115 960 9528

## JULY

24th ISEC 2000 : Including the Excluded  
to International Special Education Congress 2000  
28th An opportunity for people involved in special education from around the world to hear about best practice and new ideas, share knowledge and information in more practical ways, visit local facilities.  
Venue: University of Manchester  
Further details: Prof. Peter Mittler  
e-mail: isec@man.ac.uk  
or Congress Secretariat:  
Tel: 01942 608374

## SEPTEMBER

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

29th Riing O' Rose: Music and Movement in the Early Years  
Tuned percussion (melody and simple harmony on xylophones etc.  
Movement and dance  
Profound and Multiple Learning Disabilities  
Organised by: Special Music Courses  
Venue: Great Hucklow, Derbyshire  
Leaders: Janet Sparkes and Penny Lacey  
Further details: Kate Baxter  
Tel: 0115 960 9528

## **LEARNING PACKS**

### ***BILD Independent Study Courses***

Better Choices - Fuller Lives for People with Profound Learning Disability

Ageing Matters: Pathways for Older People with a Learning Disability

These training materials set out to help staff and first line managers meet the care and support needs of different groups of people with a learning disability. They are designed to help staff develop knowledge and skills which reflect best practice in a variety of care settings. The materials can be used in a variety of ways: for independent study by individuals; to support training organised by a service or agency; as resource materials. These courses are accredited with the Open College Network.

### ***LONGER COURSES (with accreditation)***

Interdisciplinary work with People with Profound and Multiple Learning Disabilities

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

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

University of Birmingham School of Education in conjunction with BILD

Further details: Linda Scott, tel: 0121 414 3466

M.Sc/PG Diploma in Learning Disability Studies

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

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

Further details: Stuart Cumella or Helen Bradley,

Department of Psychiatry, Queen Elizabeth Psychiatric Hospital, Mindelsohn Way, Edgbaston, Birmingham B15 2QZ Tel: 0121 627 2853

Profound Learning Disability and Multi Sensory Impairments

Two year distance learning course combined with workshops.

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

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

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

Further details: 0161 610 0149

e-mail: [jtioffice@rsd.manchester.btinternet.com](mailto:jtioffice@rsd.manchester.btinternet.com)

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

Counselling in Education - From Early Years to Post 16

This course strives to help educators reach a greater understanding of the counselling process and the skills involved in working with young people and their carers. It also aims to show how pastoral responsibilities are an integral part of a school's educational role.

The course takes place in the summer term (April to July 2000) on Saturdays from 9.00 am to 5.00pm and Tuesdays from 4.30 to 7.00 pm on the following dates:

Saturdays: 1st April; 10th June; 1st July

Tuesdays: 9th, 16th, 23rd May; 13th, 20th June; 11th, 18th July

Offered at B.Phil (Ed) (half unit) or OPQ (1 unit)

Westminster College Oxford

Further details: Pat Hill, Tel: 01865 253376

e-mail: [p.hill@ox-west.ac.uk](mailto:p.hill@ox-west.ac.uk)

## **EXHIBITIONS**

11th Nov. EC&T Resource Conference and Exhibition '99

1999 Doncaster Racecourse 9.30 - 5.00 pm.