

PMILD LINK

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

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

EDITORIAL

This theme for this issue is 'Innovation in Practice' and the articles cover a wide range of topics, some of which are truly innovative, such as the work experience project described by Chris Fuller, and some of which are developments of approaches and techniques that are tried and true, but nevertheless continue to evolve, or to be put into practice in a new way. Two of the articles look very closely at good practice in widely different spheres - residential visits and the use of objects of reference. They remind us of the need for close attention to what it is that we are actually offering to pupils/clients with profound learning disabilities.

Many thanks, as always, to all contributors of articles, letters, reviews, reports and news. Do keep writing, because it is the experiences and ideas of practitioners which makes PMLD-Link interesting and valuable to its readers.

The next issue is intended to be a forum for parents and carers, and we hope that all the articles will be written by parents. Future Focus has been written by Steve Simmonds, a member of the Editorial Group who is both a parent and a professional in the field. He sees the difficulties and successes from both angles, and I hope that what he has written will give other parents/carers courage to 'put pen to paper' and contribute to the next issue.

Don't forget that if you are trying to find information about a particular topic, or have found anything that works really well for you, you can ask other readers or share your discovery with them by sending a note to me for inclusion in the next issue.

I'm sorry that the website is not up and running (I was a bit too optimistic when the last issue came out) but it is now in the process of being designed so *perhaps* by the time the next issue comes out, we really will have our own site.

Articles

Articles or other material for the next issue should reach me by the end of October. Please send them by post or e-mail (Rich Text Format please) to:

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Work Experience for People with Profound Disabilities

An organisation based in Futham, South London, has been awarded grants from the Community Fund (formerly the National Lottery Charities Board) and Bridge House Estates Trust Fund to enable people with PMLD to take part in work experience sessions in its craft workshop. The company, itself a charity, produces multi-sensory story-packs for children, teenagers and adults with these same disabilities.

The grants were needed for materials and additional tools, mobile storage cabinets and adjustable workbenches, and to relocate electrical sockets for immobile users. It was also necessary to seek financial assistance for the enormously increased insurance liability for workers with profound learning disabilities in this environment. A further amount was put aside for transport and escorts, so that users would have every possible opportunity to be regular attendees, regardless of any staffing shortages at their places of residence.

Meetings took place with the managers of Day Centres and Residential Homes for people with learning disabilities in the Borough, and a young man of twenty eight and a lady in her early forties were recommended as people likely to be interested in the work experience on offer.

As the workers have profound and multiple disabilities, the company has set objectives for the sessions in order to be certain that everyone involved will have a sense of direction whilst assisting and working with the users.

The objectives for the users are:

- to use hand and power tools hand over hand and one to one with a supporting craft worker or care worker;
- to work with resistant and non-resistant materials, various adhesives, and paints;
- to be given opportunities to make decisions and choices;
- to be given time to demonstrate any emerging skills;
- to work beside regular workers and accept, respond to, and initiate social interaction through their individual modes of communication.

The structure of the work experience remains routine, beginning with a multisensory story, and continuing according to a written plan devised for each user, which gives the work tasks for that session (see examples at the end of this article). At the end of each session the craft worker partner records their partner's responses, and the work tasks for the following week are set. The end result is a story-pack which they retain for their own use at home, and a written assessment compiled from the weekly recording.

The work experience stories are written, as with all multi-sensory stories, to ensure that the sensory objects and materials appear in an interesting order. But most importantly for the workers' stories, is that the production techniques need to require an abnormal amount of power and hand tool use, in order to stimulate and sustain their attention and interest through vibration and sound.

The first story was entitled "Mend One, Make One!" It tells of Joe ascending the loft ladder to locate the cause of a drip, and stumbling across various treasured objects on the way. He finally finds the offending hole in a copper pipe attached to the water tank and wraps tape around it, but unfortunately puts his foot through the ceiling on the way back!

The contents attached to the A3 page cards were therefore:

a ladder, wooden chime bars, Aunt Ada's shawl!, a folding mirror, tape dispenser, copper pipe with hole, a sheet of patterned metal to represent one side of the water tank, and attached through the page card to chipboard, washed stones contained in a tin with a glued lid, (falling ceiling rubble!) plasterboard with a hole cut large enough to push through an attached trainer shoe, and a stuffed pillow and pillow case.

The production involved their drilling metal and wood, hand sawing and jig sawing various thickness of wood, chipboard, and plasterboard, hammering in clouts, nails, panel pins, using the electric screwdriver, the glue gun and the hand sewing machines. Nothing was made without their total involvement and they set the pace.

Interestingly, we have realised that the opportunities for social interaction with the regular workers are actually minimal, as everyone in the workshop is quietly busy and working hard! But the carers who attend with their residents feel that the peacefulness of the work environment is a bonus for the users. They can concentrate, and we can talk them quietly through the tasks, and hear their soft sounds, (as well as the jubilant vocalisations!) and reply and respond to facial expressions and gestures.

To instil confidence and trust in our users, the same member of staff works with them each week. This also enables the staff member to learn how best to access their partner to each tool and task, and to keep the style of access consistent. As a result of this routine approach, both users have been able to 'take over' the movement needed for using some of the tools

To our amazement, the old fashioned hand sewing machines which look like the most boring tool as far as sensory feed-back, proved to be ideal for unaided use. One of our first users, and both our current users, can now turn the handle unaided, and the young man who has very restricted arm and hand use, can pull the large silver wheel towards him, which also makes it work. He proved particularly adept at this on the mornings when his favourite female craft worker was working at the same bench! The switches on all the power tools including the electric screwdriver, are large enough to give assistance to someone who has insufficient strength to activate them unaided, but two people, one of whom has no vision, need no help except to hold the weight of the drill - but maximum supervision!

Every user has instigated their own pace for lifting and dropping the hammer and we have learnt to slow down our sawing and to use the length of the saw so that they can feel, and in some cases actually do, the pushing and pulling coactively. They have demonstrated by eye-pointing or reaching out, a knowledge of which tool is needed for a particular task, and have proved to be very interested in doing all the little tasks. For example, using the chuck key to loosen the drill bit, taking the bit out, putting a different one in, plugging and unplugging power tools, getting nails and screws out of the bag or box etc.

The company made the decision to give this time to the work experience users, and there is therefore no sense of urgency. They continue to attend until their story is complete, and as their accessing the work is of paramount importance, they can have as much time as they need.

A rewarding offshoot from all this, is that residential staff have seen multi-sensory storytelling in action and have watched their residents enjoy the adult story more each week. This has created an interest in using story-packs generally, and both our first two users regularly use their own stories at home, and were given the adult one for Christmas.

For the company, it has brought closer contact with local residents, both our users and their carers, and the borough agencies, and there is a pleasing exchange of goodwill between us all which has resulted in tangible donations of time and effort. Our neighbours in the street also like the added activity and greet the users as they pass by the workshop window.

The sessions are now an established part of company business and, as all the craft workers are part-time, our workers with disabilities are very much members of the team. It is planned to offer the experience to just two more users and then to invite each pair to return for a further period, in rotation. By doing this, we shall be giving the opportunity for techniques to be remembered and skills to be reused and perhaps developed further. The residential staff have also indicated that this workshop time is a high point in the users' week, and we could not bear to lose touch with any of them.

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Work Tasks - Tom 27/10

- sew 2 edges of pillow case
- saw chip board on mark
- drill on marks briefly (3bit)
- hammer 6 nails into marks on chipboard
- saw copper pipe on mark
- drill copper pipe on mark (large bit)
- sandpaper this hole and the ends
- attach ferrule and page cord Tom to hammer ferrule assistant hold with pincers
- jig saw rest of hole in plasterboard

Work tasks - Susan 17/11

- discuss with Susan the problem we encountered with the drilling last week i.e. show last week's effort
- saw new holder for tape from plastic tubing using small orange saw
- drill holes for split pins on marks
- Susan to hammer screwdriver into first split pin in tubing, to open it up, then assistant assemble tape holder. Susan to test that it works
- drill holes in centre of plasterboard - largest bit!
- jig saw around shape on line
- clean and tape edges of plasterboard
- stick on 'footprint'
- attach shoe to page cord and attach to page
- enlarge storyboard on photocopier
- laminate storyboard
- number pages
- assemble story in box and use

The 'Team around the Child'

A model of service for families whose child has complex needs

Everyone, from Cabinet members to local managers in health, education and social services, acknowledges the need for services to children with complex needs and their families to be more 'joined-up'. Parents of children with complex needs have been saying this for years and in the One Hundred Hours SOFTY Survey some commented :-

"I think the various professionals really need to communicate. To the parent it seems confusing how little they know about each other. I feel I am my daughter's keyworker - I find myself explaining to different staff what the others do and who they are. It's quite a responsibility when you've got enough to cope with already."

"My son doesn't receive a co-ordinated package of therapies. Many 'experts' see him and deal with their part of him and send him back to me for re-assembly."

"Dealing with the pain when you discover your child has complex special needs is hard enough to bear without having to deal with, in my case, five different agencies to provide services. I didn't have time to deal with my pain and I suffered as a result."

These parents did not get a joined up service and this caused them unnecessary additional stress. Why is that? If the professionals do not work together, whether they come from different services or the same service (e.g. health) why is it stressful for the family? We know it is, because many parents say they suffer more stress from fragmented services than they ever did in adapting to their child's condition. A list of the problems caused includes -

- parents are not given comprehensive information about available services;
- the child has to encounter each professional and each agency separately;
- parents have no single person to talk to about all aspects of the child's daily life, condition, development and learning - and no one to help them arrive at a whole and integrated picture;
- the child's daily and weekly routine might not be in the best interest of the child - and might not represent a workable balance between the needs of the child and the needs of other family members;
- the service to the child might have gaps of unmet need and some duplications - there might be unresolved contradictions in diagnosis, approach and advice;
- the pattern of appointments, clinics, therapy sessions, home visits might be chaotic and wasteful of energy and time - and result in non-attendance;
- each professional involved might not know who else is involved and what their involvement is;
- therapists, teachers, Portage workers, etc might have no opportunity to arrange joint sessions - and no opportunity to rationalise and integrate home programmes and helpful suggestions;
- professionals involved have no opportunity for informal sharing of observations, ideas, goals;
- parents have the task of passing information from one professional to another;
- parents have to repeat information continually and the child will have to undergo repeat assessments and reviews;
- support can be interrupted or ended when one professional input is interrupted - support can be interrupted or ended at a transition, e.g. into school.

Not only are parents driven ragged trying to fit everything in (and imagine all those appointments if there are pre-school siblings, if there is no family car, if there are feeding pumps and oxygen cylinders....) but, in their effort to get the best for their child, they are forced to take on the role of keyworker or co-ordinator themselves. What spare time or energy can they have for this?

Is the solution simply to provide each family with a keyworker? Yes and no. The One Hundred Hours family support model was keyworker-based and represents one way of helping the family put all the jigsaw pieces back together. In West Yorkshire, as it would be in most parts of the UK, it was a sort of first-aid; making the best of a bad job, trying to join services together for the family when there were no systems within the local services at any level for proper service co-ordination. For very many families this was a significant support and a great help, but the territory in which the keyworker had to function was never easy; though we met some very helpful professionals who wanted to work with us to co-ordinate a family's service, others would not budge an inch from their traditional fragmented approach.

The keyworker will function best when she can work at grassroots with the family within a system in which there are other elements of co-ordination at various levels. Keyworking is not a substitute for service co-ordination. Effective keyworking requires that the locality have a system of service co-ordination providing a favourable environment and a constructive context within which the keyworker can work.

So what is 'proper service co-ordination'? When it comes what will it look like? There are no answers to this in the UK yet, though there is a new parent/professional network which aims to promote co-ordination and spread good practice. In my view the opportunities to co-ordinate services (health, education and social services and the independent/voluntary sector) include the following -

- multi-agency funding for provision of comprehensive information to parents;
- multi-agency funding for the processes of referral, assessment, service delivery and review;
- multi-agency funding for one or more posts to develop and manage service coordination;
- multi-agency funding of a centre or unit for children and families;
- multi-agency collaboration (but without shared funding) in provision of comprehensive information to parents;
- multi-agency collaboration in the processes of referral, assessment, service delivery and review. Collaboration in these processes can result in a single care pathway for children and families.
- multi-agency collaboration in a centre or unit;
- provision of a keyworker, part of whose role is to facilitate a co-ordinated multiagency service to the individual child and family;
- a 'team-around-the-child' approach by multi-agency professionals. This is a model of service in which the small number of professionals who see the child regularly to provide treatment, education or therapy, work closely together to provide a coordinated service to the individual child and family. The team-around-the-child (TAC) is an individualised team and is unique to each child.

While the keyworker model is often the first one service managers think of when trying to achieve joined-up services, it does present the major problem of having to find enough money to build a new professional team which is big enough to meet the needs of all the disabled children and families in the locality who are suffering from a lack of co-ordination. This will surely

come, but not while children with disabilities and their families are considered to be only a low priority for funding.

In the meantime most keyworker projects depend on particular busy professionals taking on the role of keyworker/co-ordinator for a number of families and adding this work to their existing role as therapist, paediatrician, health visitor, social worker, pre-school teacher, etc. It is a very positive move forwards and the commitment of the workers is great and admirable. However there are inevitable pressures and conflicts in time management. The keyworker/co-ordinator has a very demanding role. She will need to know she has enough time to spend with the family and then to do the follow-up phone calls, letters and meetings. She will need some clerical support. Most importantly she will need support for herself; somewhere to off-load all the emotional weight she will bring away from her close work with families. When the keyworker has a dual role the likelihood is that she will be under-resourced, with consequences for the service to the family and her own professional satisfaction in the role.

A growing number of local authorities are looking instead to the team-around-the-child model as a first practical step towards service co-ordination. Though the TAC is a collaboration between involved multi-agency professionals, it is not just another 'case conference'. It is smaller, more frequent, more informal, more 'grassroots' and more 'family-friendly'. Taking as an example a pre-school child with cerebral palsy and associated conditions, the TAC might consist of relevant therapists, health visitor, sensory-impairment teacher, Portage worker, nursery nurse and, perhaps, social worker from the Children with Disabilities Team. Members of the TAC are the people who see the child regularly, provide very practical intervention and know the child and family very well. The other professionals involved will be the 'peripheral' group and will be kept informed about the work of the TAC. As the child's needs and situation changes so the TAC will gradually change its composition with individual professionals in TAC and peripheral group changing places. The parent, of course, has a full place in the TAC which he or she can take up when ready.

The TAC is democratic; it decides how often and where to meet and who else should be brought in. It might meet every two or three or four months, perhaps more often when there are more issues, and will feed in to the more formal conferences and reviews. It is a real 'team' in the sense of being supportive to all of its members and its general tone is positive, encouraging, affirming. At its meetings the TAC members can share information and observations, jointly address any new issues, share ideas about goals and programmes, rationalise the daily and weekly timetable, arrange for any joint visits and agree a service plan for the period up to the next meeting. At the end of the meeting, a date is agreed for the next one so that there is no need for anyone to spend time ringing round to fix a date. Notes, including the written multi-agency service plan, are written up and distributed to TAC and peripheral group members.

The TAC can happen whether or not there is a shared base for professionals. But if there is a Child Development Centre or other Unit then some meetings might happen there and such a Centre or Unit might be the ideal administrative nucleus for the TAC system. And a proper 'system' it should be. The TAC system should be properly planned, resourced, documented, and monitored and made available to all families in the locality who meet the criteria. A team-around-the-child system, established as a first move towards service co-ordination, cannot happen in a vacuum anymore than a keyworker model can. There will need to be senior management approval across the agencies, a multi-agency committee to oversee the work and a co-ordinator for the system.

So which is the best way to start service co-ordination, with a keyworker model or with a team-around-the-child model? The answer to this will depend on many factors including what is already happening in local services, the preferences of parents and professionals and the funds available. The choice does not have to be 'either-or' because the two models complement each other. In the One Hundred Hours model, it was a natural first step with some families to facilitate the development of an informal TAC. Once it was in place it provided an ideal context for many of the keyworker's roles. Conversely, one member of the TAC will need to take on the function of team leader to chair meetings and distribute notes and this leads naturally into a keyworker role. So the keyworker can generate a TAC for a family if there is not one already in place and in the same way the TAC can generate a keyworker, define her role for the family and provide a context for her work.

This year's Handsel Trust national conference will focus on 'joined-up' working and will feature keyworking, the team-around-the-child and the role of Child Development Centres setting them within the wider context of multi-agency service co-ordination.

Peter Limbrick

Peter Limbrick BSc. Peter's background is in special education and he was founder, director and keyworker for One Hundred Hours. He now chairs the Handsel Trust, a UK charity which promotes effective support for families of children with disabilities throughout the UK. He is a member of the steering group of the new Care Co-ordination Network UK. Peter works as a service development consultant to UK statutory services.

Contacts and Information

Information about the One Hundred Hours keyworker-based model of family support is available from The Handsel Trust, 83 Silver Street, Kings Heath, Birmingham, B14 7QT. Tel/fax: 0121 441 1580. Email: handsel@LineOne.net

Parents' Support Needs: The views of parents of children with complex needs. Gudrun Limbrick-Spencer ISBN 1 903745 01 2 Price £6.00.

Parents' Support Needs is based on the words of parents from the UK SOFTY Survey - a national postal survey which asked parents of children with complex needs for their views of support. The recommendations are wide-ranging and encompass a keyworker role. The report also details the One Hundred Hours model of support. Available from The Handsel Trust (see above)

Care Co-ordination Network UK: Katy Barton, SPRU, University of York, York, YO10 5DD. Tel: 01904 433605. Email: kb17@york.ac.uk

One-day Conference: Focusing on the Family,
City Hospital, Birmingham.
Tuesday 16th October, 2001.

Information and booking forms from Conference Organiser,
The Handsel Trust, 15 Haversham Court, Middleton Road, Manchester M8 4JY.
Tel/fax: 0161 7407757. Email: p.limbrick@u.genie.co.uk

The value of Residential Visits for Pupils with PMLD

Introduction

Having moved last Easter I found myself without employment for the Summer Term. Knowing this my previous school, a 2 to 19 school for pupils with severe learning difficulties (SLD), invited me back to take part in three residential visits with different classes. Residential visits have always been regarded by the school as a valuable and integral part of each pupil's education and every effort is made to ensure that everyone is able to attend. As I was also undertaking an MEd course at Birmingham University in Learning Difficulties this prompted me to look more closely at the value of residential visits for pupils with SLD and specifically at the value of the school residential visit, in terms of its educational content, for pupils with profound and multiple learning difficulties (PMLD).

Setting the context.

The residential visit was with a class group of eight children with PMLD with ages ranging from 5 to 15. They were accompanied by the regular full time staff of the class consisting of two teachers, who job share, three Special Support Assistants and a student. The group was completed by the school's Language Specialist, who helps them regularly at mealtimes, and myself. Apart from working in the school for eight years I had spent a term in this class four years previously and so knew most of the pupils reasonably well.

We were based at a country hotel in Dorset that had been visited by two of the support staff prior to booking. This was three hours travelling distance from the school so we left on the Monday morning and returned on the Friday afternoon. We stayed in an annexe of the hotel, occupying a group of ground floor rooms around a central courtyard. This was ideal as most of the pupils had wheelchairs and, as each adult was sharing a room with their particular pupil, there was easy access of communication between the rooms when help was needed with lifting and medical procedures. Breakfast and the evening meal were taken together in the hotel's dining room, whilst the days were spent visiting attractions in the area.

There have been very few studies into the value of residential visits, as opposed to Residential Homes, for pupils with SLD. Most of the published literature concerns residential visits for mainstream pupils, in particular the value of Outdoor Education, but I feel that there are important parallels with and implications for, residential visits with pupils with SLD. The three main strands I looked at were the use of the residential visit

- for teaching Personal, Social and Health Education (PSHE)
- for developing the 'whole child'
- as a means of providing effective learning opportunities.

It is important to note that these three strands are not mutually exclusive and in fact overlap each other in a number of ways.

The use of the Residential Visit for teaching PSHE.

With the introduction of the new PSHE guidelines schools will have to provide a 'wide range of activities and experiences across and beyond the curriculum' (DfFE, 1999) and so in order to cover these programmes of study perhaps we need to look again at the opportunities provided by residential visits. PSHE within SLD schools is often concerned with individual programmes of study that address specific self-help or independence skills and these can often pay little regard to contexts proving that there is a need to extend opportunities and make them more relevant for the individual. An obvious example is an activity such as cleaning teeth which is far more relevant when carried out on a residential visit as

part of washing in the mornings and at night than it is on arrival at school when the pupil may have already cleaned their teeth that morning.

It is important to be aware that within the field of PSHE major choices and decisions about desirable personal and social qualities are being made by schools and teachers, especially for pupils with PMLD who may not be able to express their own preferences, and so staff may need to reconsider which qualities are wanted and how desirable they are (Hargreaves et al 1988). By its very nature there is a need in PSHE for a broad and balanced curriculum content delivered through the flexible use of teaching approaches. The residential visit with its widely differing conditions and experiences can perhaps give pupils a breadth of opportunity not readily available within the classroom setting and provide an 'intensive context' (Taylor 1988) for PSHE.

The use of the residential visit for developing the 'whole child'.

Another factor to be taken into consideration when looking at the experiences on offer on the residential visit, is are they actually developmental for the child (Best 2000) or are they merely designed to make the child more socially acceptable (Rose et al 1994). Teachers need to ensure that each pupil is given the opportunity to reach their full potential which in turn should help to promote the development of the whole pupil. In order to do this each pupil needs to be given the opportunity to extend their knowledge and experiences in order to build up their self reliance, self esteem and self confidence.

The residential visit can be the vehicle for broadening the range of experiences on offer to pupils by placing them in new environments and in new situations. By taking on new challenges pupils have the opportunity of developing their personal qualities and characteristics. Such experiences can help them to face the unpredictable and release innate and dormant qualities, as well as allowing them to generalise what they have already learnt to new situations.

If, as Ware (1996) suggests, 'It is through our interactions with others that we learn who we are' then residential visits where pupils are placed in situations that encourage social interaction and independence must be beneficial. Lacey (1998) argues that the pupils with PMLD have a greater need for a range of relationships and so residential visits can give pupils the opportunity to communicate with a wide range of people in different circumstances and allow the building of relationships. The residential visit also allows time for relationships, especially between pupils and teachers, to develop. Marland (1974) stresses the importance of establishing these teacher/pupil relationships in order to allow more effective teaching.

Pupils with PMLD often take longer to respond to situations and the more responsive environment of the residential visit can provide this time, away from classroom routines and the demands of the curriculum. The residential visit can give the teacher the opportunity of seeing the pupil as a whole person beyond the constraints of timetables and specific curriculum objectives.

The use of the residential visit as a means of providing effective learning opportunities.

Can the residential provide a greater diversity of opportunities for learning than the classroom? I believe that they can be used as a means of providing effective learning opportunities as long as they are relevant to pupils' day to day reality and have clear meaning and purpose. To be effective a residential visit needs a great deal of planning and preparation prior to departure so that there are clear aims and objectives for each individual, which take account of their present interests, aptitudes, experiences, and skills and build on them. Residential visits are seldom cheap and so they need to be seen to be achieving these aims and objectives so that they become: 'the most cost-effective use of resources likely to achieve desired outcomes' (Taylor 1988).

Often the discovery of new interests on the residential visit can be used to change programmes to provide more appropriate learning goals. An evaluation of the visit, by both teachers and pupils, in terms of how far the aims and objectives were achieved can lead to improvements in the planning of future visits.

Residential visits and their success depend greatly upon the reliability, responsibility and enthusiasm of the staff. Each staff member needs to be conscious of how they can use the residential as a planned resource to supplement and extend the scope of the curriculum. For these reasons it is better that staff who already know the children well should accompany them on the trip to ensure continuity of learning. Residential visits are not only a learning experience for pupils, but are invaluable for staff. Often these visits with their more relaxed atmosphere, and movement away from rigid personal and school regimes, allow teachers and pupils to develop relationships which can increase understanding to the mutual benefit of all on return to the classroom. It also gives staff the valuable opportunity of being able to simply observe a child without the pressures of the classroom impinging. This can bring about the creation of a more responsive environment where there are greater opportunities for interactions to occur. In the classroom one to one interactions are often very short owing to the intervention of other children, interruptions and the main focus being on the completion of a task rather than the interaction for its own sake, and this can be particularly detrimental for children with PMLD (Ware, 1996). However, a residential visit with twenty-four hour contact can offer a plethora of one to one interactions of many different kinds and duration.

Many authors (see Taylor, 1988; Farnham and Mutrie 1997) stress the importance of learning through experience and the greater ability of such visits to provide both planned and unexpected opportunities to widen a pupil's experience.

If residential visits are to be used as effective learning opportunities then another aspect that needs to be considered is the matching of the individual's objectives to the activities on offer, whilst remembering that spontaneity and flexibility are essential if unique opportunities are not missed, but are used to further enhance learning.

It is also important to follow up the experiences on return to school so that the visit is not seen, by pupils and staff alike, as a one-off, but part of the whole school curriculum providing a valuable and meaningful learning experience for all involved. Farnham and Mutrie (1997) have also suggested that residential visits, for some pupils, could bring about a break in learned behaviours and thus allow change to take place. Such changes should be followed up after return and there should be some investigation into ways of reinforcing the learning.

'Andrew' - a case study.

'Andrew' is a 13 year old boy with PMLD who has cerebral palsy and is microcephalic. He has daily petit mal epileptic fits and absences. He is a wheelchair user and wears a body jacket which, while supporting his spine, constricts his movement and so can only move with help. He has no speech and his very limited communicative intentions are not easy to understand. 'Andrew' is in many ways an extremely complex young man.

Whilst on the residential I designed an investigation the aim of which was to carry out observations of 'Andrew' to see if his reactions to the activities being presented could be tied into the breadth of opportunities laid down in the PHSF curriculum (DFEE, 1999). Before leaving for the residential I picked out from the documents statements relating to making choices and developing relationships with the intention of seeing how far these aims could be achieved on the visit. 'Andrew' is still at the pre-intentional stage of development and so I was aware that any attempts to measure his reactions to specific events were likely to be extremely subjective. Although the investigation took place over too short a time to draw any firm conclusions, especially as 'Andrew', a pupil with PMLD, would possibly need longer to respond to new situations, from a subjective point of view, 'Andrew' was seemingly starting to respond more positively to me when he was distressed by the end of the week. I felt that allowing himself to be comforted by an unfamiliar adult was a good indicator of the building of a relationship.

Taking into account the three strands detailed earlier this residential visit was useful for carrying out part of 'Andrew's' programme for PSHE as I feel that I did manage to start to build up a relationship

with him. PSHE is only a small part of the overall curriculum and one could argue that using a residential visit to cover such a small aspect is not at all cost effective. A relationship could have been built up within the classroom, although I feel that it would have taken a lot longer as the visit provided a more responsive environment with more opportunities for quality one to one interactions. Perhaps it could be justified in this case as the building up of relationships with different people is very important to 'Andrew' as a means of developing his communication and as part of his overall development as he spends quite a lot of time in respite care.

'Andrew' was given the opportunity to develop as a whole person as all aspects of his care and education were able to be addressed, by the same person, in a wide variety of real life situations. The visit brought to light a number of issues to myself and to the teachers who were leading the visit. Although I had been 'Andrew's' designated carer on a previous residential visit I was acutely aware at the beginning of the investigation that I knew very little about 'Andrew's' present needs. The production of individualised passports for the pupils containing basic information such as medication, likes and dislikes and methods of communication were seen as being a priority for the next term. Many of the pupils in the class, including 'Andrew', spend some time in respite care and so are seen by a number of different carers and such passports would help to ensure that they received more consistent care.

Conclusion

Looking at the wider picture of the value of residential visits, I feel that if they are properly planned, they can be used to broaden horizons and give an extra dimension and depth to the curriculum that is not available in the classroom. They can provide a realistic context in which to place activities and can help to implement many of the cross curricular themes of the curriculum in a more realistic and relevant way for the individual pupil. With its greater breadth of opportunities a residential visit can bring out in pupils attributes and abilities that have not been recognised in school and can also help the staff to gain a greater insight into the whole child. I would agree with Marland (1974) when he states that: 'Residential can be the means by which a pupil can be assisted to enrich their personal life and at the same time support the subject teaching within the curriculum.' However, it must be stressed that, without proper planning, there is a danger that the unique value of the residential visit can be lost and it become merely an expensive form of respite care.

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References

- Best, R. (2000) *Citizenship and Personal and Social Education* an unpublished paper presented at the SHMIS Summer Meeting, Reading Blue Coat School.
- DfEE (1999) *The National Curriculum for England: Non-statutory frameworks for Personal Social and Health Education at Key Stages 3 and 4*. DfEE and QCA
- Farnham, M. and Mutrie, N. (1997) The Potential Benefits of Outdoor Development for Children with Special Needs. *British Journal of Special Education* vol 24, 1, pp.31 - 38.
- Hargreaves, A., Baglin, E., Henderson, P., Leeson, P., Tossell, T. (1988) *Personal and Social Education - Choices and Challenges*. Basil Blackwell Limited
- Lacey, P. and Ouvre, C. (Ed) (1998) *People with Profound and Multiple Learning Disabilities*. David Fulton Publishers
- Marland, M. (1974) *Pastoral Care*. Heinemann Educational Books Limited.
- Rose, R., Fergusson, A., Coles, C., Byers, R. and Banes, D. (1994) *Implementing the Whole Curriculum for Pupils with Learning Difficulties*. David Fulton Publishers.
- Taylor, M. (1988) *Residential - A Resource for Learning*. National Foundation for Educational Research.
- Ware, J. (1996) *Creating a Responsive Environment*. David Fulton Publishers.

Interaction Reaction

Keeping Intensive Interaction Going

Sometimes it takes someone with a bit of simple common sense to point out the obvious! This is certainly what Melanie Nind and Dave Hewett (1994) did for me with their first book on Intensive Interaction. Reading the book feels like beginning to see through a mist of useless, disempowering theories and rubbish and replacing supposed knowledge with a basic respect for the humanity and personalities of people with Profound Learning Disabilities.

Intensive Interaction is not rocket science. The reaction of people attending courses varies between relief that they are now being given permission to behave naturally and intuitively and astonishment that they have to go on a days training to learn what they already know.

I don't intend to go into great detail about the theoretical background, discovery and research on Intensive Interaction (in the assumption that most readers already have this knowledge). What I want to relay to readers is the way in which Intensive Interaction is being used in adult services for people with learning disabilities in Somerset.

If Intensive Interaction is new to you I hope this will whet your appetite to seek more information - or even begin experimenting yourselves!

Intensive Interaction is an approach to spending time with people which borrows the style of a parent/carer of a young infant: - spending rich time in face-to-face interactions with no agenda except to enjoy each other's company, converse with each other on a level which is meaningful to both - giving the person with profound learning disabilities the clear message that they are good to spend time with.

Many people with PMLD have skills equivalent or similar to a typically developing child in their first year. Using the style of carers of young children can aid in increasing emotional security, self-esteem and a sense of self-worth. This can, in turn, encourage further development in areas such as communication, cognition, physical and sensory skills and sociability.

For many of the individuals with whom we are working, this first year's experiences were missing. There are an estimated 232 adults with PMLD receiving provision from social services. Around half of these people were admitted into large wards in long-stay institutions before the age of one, thus missing the communication-rich environment which distinguishes that of a most typically developing children

Intensive Interaction was introduced into Somerset five years ago in a project with fourteen service users (Irvine 2000). The results and the unfolding of these people's lives were so exciting that staff groups around the county began to ask for Intensive Interaction to be used in their work places.

While Intensive Interaction itself is highly enjoyable, intuitive and spontaneous we recognised that sustainable use of this approach across the county would require some organisation. The initial project had required a great deal of support in order to monitor progress and maintain motivation in the staff group.

The tendencies of the staff were to become frustrated by what still needed to be achieved rather than identifying and celebrating what had already been accomplished. They had needed an

'outsider expert' to encourage them to review records and videos and to recognise the quality and the efficacy of the work they were involved in.

Progress brought with it another aspect of necessary support. Comments like: -"He used to be so easy to work with but now he's really demanding!" demonstrated that individuals had learned enough to be communicating with more self confidence. Staff needed support to view these incidents as positive but they also needed guidance about moving on: - introducing boundaries and more formal communications.

The support for the project had been mainly provided by myself (a speech and language therapist), but if the use of Intensive Interaction was to be extended, neither the speech and language therapy team nor the psychology team could commit an adequate amount of time to achieving sustainable implementation of the approach. There was also a strong feeling that as Intensive Interaction is an intuitive, natural approach, the involvement of therapy 'experts' should not be required. The people who were mostly involved were social services staff and the expertise should be transferred to this organisation.

A multi-disciplinary working party was set up to examine how Intensive Interaction could be extended across the whole county of Somerset adult services. The results of these discussions were that sixteen social services staff would be appointed as I.I. coordinators. Any success was surely going to be dependant on the quality of the people appointed to undertake this role and great care was taken to ensure that we got the best

The Selection Process Consisted of:

An application form, including 500 words on I.I. and the Coordinator role

Signed agreement from line manager and senior management for application

Agreement for application from each Community Learning Disability Team

The production of references from colleagues and managers

A structured interview with panel of three: two senior social services managers and a speech and language therapist

The Training Consisted of:

A case study of one individual, including creating a core-team and setting up a contract

Communication development

Cognitive development

'Deviant' development

Theoretical comparisons to other approaches

Organisational change

Team-building

Problem solving

Assertiveness

Use of Video and editing techniques

Teaching & learning styles

Autism

Challenging behaviour

These sixteen individuals have just completed a year's preparation to enable them to offer the initial training in Intensive Interaction in conjunction with the ongoing monitoring and support of the approach.

Alongside the work in developing the Intensive Interaction team, the working party examined operational structures, which would ensure support for the people involved.

One of the most contentious support systems to be adopted was the use of contracts which required signatures from everyone who was to be involved in using, supporting and monitoring

I.I. Use of the contract meant that we could prioritise the training needs of the teams involved, ensure that management support was agreed, negotiate standards around record-keeping and videoing and that regular reviews were planned.

However, there were some reservations about using something as formal as a contract to monitor an approach that is basically spontaneous and fun. We had had some experience of using I.I. with an individual very successfully until there had been major changes in the staff team, including a new team leader who was unfamiliar with the underlying philosophy of I.I. These staff changes had a devastating impact on the service user. By the use of contracting we are hoping that this situation will never be repeated.

The role of the I.I. coordinator was to create a 'core team' around an individual, role model good use of I.I., set up the record keeping systems and hold regular video review meetings with the core team. The coordinator could be directly involved with the implementation of I.I. if needed during the initial stages. The long-term aim was for them to be able to gradually withdraw and leave the responsibility mainly with the core team. The coordinator's responsibility following withdrawal was to formally monitor on a twice-yearly basis but to be available should further support be necessary.

The Intensive Interaction Co-ordinators are released from their usual duties within Social Services for two days a month to fulfil their role. In the first year they will be expected to set up I.I., care teams and contracts with two individuals.

Simple maths should tell us that at this rate it will take years to reach 232 people with PMLD! However, Intensive Interaction brings with it an underlying culture of working with people that is respectful, accepting and empowering. Contracts will not be responsible for seeing the expansion of these qualities in a service - the culture is already changing as staff see the changes in individuals with PMLD who have benefited from Intensive Interaction. We desperately don't want Intensive Interaction to be a temporary fad. We want to set up Intensive Interaction support that is sustainable. This process has taken five years so far and may take another five years to fulfil.

We all enjoy and recognise the benefits of Intensive Interaction. Sustainability of the approach is worth ten years of focused effort.

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References

- Irvine, C (1998) Addressing the needs of Adults with Profound and Multiple Learning Disabilities in Social Service Provision. In: Hewitt, D and Nind, M (1998). *Interaction in Action: Reflections on the use of Intensive Interaction*. London: David Fulton.
- 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

Affective Communication Assessment: An Owners Manual

Since the Affective Communication Assessment (Coupe, Barton, Barber, Collins, Levy & Murphy 1985) or ACA was published, our understanding of how social encounters can support affective communication has matured, enabling the contributions of the less skilled communicative partner to be involved in meaningful turn-taking or burst-pause interactions. The practice of Intensive Interaction (Hewett & Nind 1994) has provided an excellent awareness of social encounters around which the reactions of the intellectually disabled communicative partner can be the central and shaping factor of the encounter.

Pre intentional behaviour however, is just that, communication without intention. The learner is unaware of the communicative nature of his/her behaviour and is reacting without intention, ie responding to internal states. The communicative partner provides a responsive context for the behaviours, giving the interaction the appearance of intentionality.

The skill of the special educator or therapist is to react to these affective responses, or expressions of internal states, in such a way that the learner becomes aware of the significance of their behaviour. Through reacting responsively and by providing social consequences to the behaviours, we can assist our clients to recognise that they are able to generate consequences and initiate sequences of events that are more interesting and motivating than the internal or sensory events that they can provide for themselves.

The ACA is still a useful tool to enable practitioners involved with people who have profound and multiple learning disabilities to recognise how their clients react to experiences. By responding to the behaviours we see in association with positive and negative preferences as if these repertoires were intentionally communicative, the learner is placed at the fulcrum of the exchange. Their reactions dictating how the exchange progresses.

This 'Owners Manual' explains and illustrates the use of the ACA.

The Affective Communication Assessment is a practical tool that enables users to pinpoint what a person 'looks like' when they like something, or dislike, reject or want it. The Assessment provides information which can contribute to the development of both more successful social interactions and more successful interventions.

It has already be said that it is often difficult to understand or 'read' the reactions of people who have multiple and profound disabilities, as they frequently experience involuntary or uncontrolled movements, or move in idiosyncratic patterns. The ACA sheets help to structure the manner in which an observer first, watches the reactions of a client and then, decides whether the client has enjoyed the encounter or not.

The idea of the assessment is threefold: to gain a resource of encounters that the client enjoys and will communicate about; to accumulate information about how the client reacts to experiences, so that inferences about whether they enjoy, want, reject or refuse specific encounters may be made. Once this information is amassed, inferences about whether they like, reject, want or dislike further, new encounters may be made.

Before the paper exercise begins however, it is useful to go to the client's parents or carers, significant people in their life, and others who know the client well to find out what the client likes or responds to. These people will often know specific positive or negative preferences (eg particular drinks, tastes or sounds) that the client has. These people might also be able to tell you how they feel that the client expresses their likes and dislikes.

While the ACA is a principled assessment, it is not necessarily an objective assessment. When clusters or 'repertoires' of behaviours thought to infer pleasure (eg the person smiles, looks to you and then vocalises) occur consistently when a client is given a taste of buttered toast, it is considered fairly safe to assume that, when the client consistently reacts in this way when given a

segment of chocolate, they like the chocolate too. When long standing or significant people in the client's life advise you that eg 'Frank likes sweet tea but hates sweet coffee' it is worthwhile including these two items in the presentations to be included in the assessment as they provide a 'metre' against which other reactions can be compared.

Before embarking on the assessment it is also worthwhile to either

- find someone to help you to do the assessment; it is very difficult to give the presentations as well as observing and recording the client's reactions, or,
- use a video so that the observation sheet can be scored at a later date and, more importantly, you can watch specific 'difficult to gauge' reactions a number of times if you need to.

The first part of the process of assessment uses the Observation Sheet. Along the left hand side is a vertical list of descriptors which you will use as reference points to record the physical and/or vocal responses which you observe. It is worthwhile becoming familiar with the order of these before embarking on an assessment so that time is not wasted looking for the correct square to mark on the sheet, when you should be looking at the person being observed. At the bottom of the sheet are spaces open for you to record your interpretation of the client's behaviour eg 'strong like', 'interested', 'not like', or 'neutral', that is, how you thought the client felt about the presentation.

The ACA is an assessment that is based on observing client's physical reactions, repertoires and responses (or affective reactions) to experiences. The observer is looking for consistent patterns of reactions so that inferences can be made about whether an encounter or presentation is enjoyed or rejected. These presentations should involve as broad a range of experiences as is possible, including for example:

- *tastes* - 'known' preferred tastes, sweet, savoury, moist and crumbly foods (NB ensure which consistencies of food are appropriate for the client with speech and language therapist, or parents/carers)
- *sounds* - significant sounds in the person's life; parent/carer voices, family pet noises, sounds from the person's life such as home sounds, school bell, or the voice of a bus escort, lunchtime worker or friend, preferred TV themes, types of music, unusual sounds and, in addition any idiosyncratic preferences that the person is amused/engaged by (eg sneezing or laughter) if possible, the person's own vocal sounds.
- *aromas* can be particularly significant for people with visual and/or hearing disabilities. The routinely worn perfume or scent of a significant person in the client's life, or the smell of coffee or a particular food might arouse the client or produce a positive reaction of recognition.
- reactions to *touch* can often be strong and defensive from visually disabled clients. You should be very careful that the client is not startled or surprised by any type of touch or tactile presentation (eg hand massage, hair brushing, a fan blowing air across the face etc).

Using video or an assistant to record or 'code' the client's reactions, the presenter should work with the client, spacing the presentations so that the response from one presentation does not influence the next. If the client can still sense the taste of a previous presentation (eg strawberries) while receiving the next one (eg marmite), the tastes may clash promoting a reaction to the two tastes rather than to the specific presentation. It is important to give the client time and not to bore or confuse them.

The ACA need not be done as a specific contact session, if the observer is well organised, some parts of it can be carried out during the client's day (eg lunchtime, bedtime) that is appropriate to the presentation. The later, Identification Sheet will enable the user to ensure that it was the specific presentation rather than the context of the presentation was the source of the reaction. That said, it is frequently valuable to give some presentations one after the other, as, whether the person is prepared or eager to accept a second taste of yoghurt is an indicator of whether they

enjoyed it the first time. It is also important to know whether they are anticipating or 'reading' events going on around them, as this is vital to informing the style of interaction in the final stage of the ACA.

You might use up to 10 *Observation Sheets*, there is no correct number. You will know that you have enough when you find that you can recognise the telltale clusters of behaviours that consistently happen in relation to positive and negative preference and are thus able to infer whether the client enjoys or dislikes an encounter or experience. When you look at the Observation Sheet you will probably notice that the client uses some movements more than others - ie some rows are used more than others, and that some types of response are more vigorous, involving more movement than others, ie some columns are more full than others. If you look at this information you will hopefully note that some regular patterns of behaviour correspond to regularly inferred likes, or dislikes. Your interpretation of 'Strong like' might correspond to the regular appearance of localisation/search behaviours or increases in hand or body movement. At the same time, what you interpreted as 'Strong dislike' might correspond with increased head movements away from the presenter, the closing of eyes or mouth and increased mouth activity. Look for regularities between the involved body movements and the interpretation of the client's behaviour.

The next, *Identification Sheet* is designed for you to test your observations. The presentations that promoted the strongest or most consistent reactions can be presented again in more controlled surroundings. This process allows you to confirm that the responses observed were made in reaction to the actual presentation and not the person doing the presenting, or the manner in which it was presented.

The Identification Sheet is different from the Observation Sheet in that there are no descriptors. It is recognised that the descriptors might not be specific enough to cover all types of reaction and these spaces were left open so that descriptors might be tightened up to fit the client's reactions better (eg Hands/'finger activity' on the Observation Sheet might be split into Hands/'fingers straight/fist made/repeated pattern of movement', on the Identification Sheet).

When you are sure that you have identified some consistent indicators of how your client reacts with pleasure or displeasure and you have identified a number of encounters or types of encounter that your client consistently reacts to, you can safely say that you have begun to get a fix on how the person you have observed, communicates affectively.

The ACA *Summary or Intervention Sheet* provides a grid in which the stimulus, or presentation, is written. In the following space the Affective Communication or your interpretation of the behaviours you saw, is written. In the next square there is a space for the descriptors or consistent behaviours to be looked for. Lastly there is a square to describe the adult's response to the client's behaviour. The grid now describes a context in which your client responds to an experience, which is acknowledged and acted on:

Using the data from the ACA

Everyone reacts to the events that they experience. If we like something we react in one way, if we don't we tend to act in another different way. These reactions are not an attempt to tell those around us that we like or dislike an experience, we are simply reacting. Even so, our physical reactions are visible to others and so, inferences about our 'state' can be made by those observing us. This is unintentional communication. However unintentional, if the reaction is acknowledged by those around us, our reaction can be said to have been communicative, or, because of the responses of others to the reaction, placed in a communicative context. For example:

Stimulus: John is given a taste of marmite on toast

Affective communication He likes it / wants it

Repertoire of behaviours His tongue activity increases, his mouth closes as he chews, his head moves from side to side and he makes vocal/nasal sounds. His hand movement increases, although his fingers relax from their typical fist position. When he has swallowed, he smiles and his head returns to the mid line again

Adult Interaction John is offered another piece of toast

Results John's behaviours have indicated to the carer that he likes the snack on offer. His continued relaxed posture has indicated that he might like some more. This has resulted in carers offering more .

When Chantelle, a 15 year old with a visual disability and PMLD is given a drink of orange juice, her left hand rises toward the cup and she opens her lips to allow some liquid in, does so and then takes her mouth from the cup, swallows and turns her head to the direction from which the cup came and stills. This is interpreted as her liking the drink. She is offered another mouthful, which she takes in a similar way. If however she is given a drink of milk, her left hand rises toward the cup and she opens her lips to allow some liquid in, does so and then drops her hand into her lap, and opens her mouth to allow the liquid to escape from her mouth. Her mouth then closes and she stills.

At this point, we can assume that Chantelle did not like the milk (which she allowed to leak from her mouth) as the observation sheet showed that when she drinks something she does like, she swallows it all. Additionally when she enjoys a drink, her hand lifts toward the cup and sometimes touches it, and having had a pleasant taste, she orients her head to the direction from which the drink came. Whereas in the case of milk we do not get these positive indications.

When you find a presentation that the client does not like, it is often useful to contrast it with one that they do like to highlight the communicative process and turn a reaction into a communicative diad:

If Chantelle is given a number of consecutive mouthfuls of a drink that she likes (eg orange juice), she will respond in a similar way to each of them. If she is then given a taste of milk, her behaviours will change to those associated with the taste not being liked. Within this context, if the presentation is then changed back to the orange juice, Chantelle's reaction will have been placed in a communicative context, and she will have experienced the effect of her behaviour. She will have effectively stated a preference. Her experience of the encounter is one of having exerted control over the presentation of something she did not like, changing it back to her preferred experience.

The ACA data then, gives a structure to the observations we make when trying to decide whether someone is showing a positive or negative preference for an event or experience. Once we can safely recognise the behaviours that seem to indicate want or not want, like or dislike, we know what responses or repertoires to look for from the person during novel encounters. The data also provides a resource of information about the client's likes and dislikes that can be used to structure social interactions so that the client's responses are reacted to in a predictable and consistent manner.

By placing the actions of the client at the centre of the interaction, we are creating the circumstances where the behaviours of the client shape the actions of those around them. By creating circumstances in which expressions of preference are acknowledged and acted on throughout the client's day increases the chances that the client will ultimately associate their own actions with the changes that follow. This leads to the client beginning to control their environment through social means.

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References

- Barber, M. (2000) *Skills, Rules, Knowledge and Three Mile Island. Accounting for failure to learn among individuals with profound and multiple learning disabilities*. Un-published PhD Thesis. Manchester Metropolitan University
- Coupe, J., Barton, L., Barber, M., Collins, L., Levy, D., & Murphy, D. (1985) *Affective Communication Assessment*. Manchester Education.
- Nind, M., & Hewett, D. (1994) *Access to Communication: Developing the Basics of Communication with People with Severe Learning Difficulties Through Intensive Interaction*. London: David Fulton

Communication with Objects for Reference

Use of objects of reference to express needs

This paper explains how 'objects of reference' have been used in communication systems with children with profound and multiple learning difficulties drawing in particular on the writings of Adam Ockelford and Keith Park. Of course, they have been used with adults too, as both describe in their writing, so take it for granted that what is described below also has application for adults.

Objects of reference are commonplace objects which may stand for something in the same way that the spoken word does. For example, a child who cannot understand or say 'drink' may be able to use, or understand a communication partner using a cup to express the same idea. The object used may form part of what it stands for: for instance, 'ball pool' can be represented by a ball from the ball pool or 'swings' by a piece of chain. Some objects may be an essential feature of the activity: for instance, 'horse-riding' may be represented by a stirrup, 'lunch' by a spoon and 'shopping' by a coin. Some objects may not be a physical part or an essential feature but may be closely associated with what they represent: for instance, a particular classroom may be represented by a bell which matches the bell attached to the classroom door.

It will be necessary to engineer frequent opportunities during each day to teach children the association between an object and the referent. One possible way of establishing the connection is to teach children to hand over, or touch, or even just look at an object, and then immediately give them the reward of the of the associated activity or person or thing. Other principles are probably crucial to the success of teaching at this early stage. Firstly, objects of reference should be as closely linked as possible to the thing which they represent. Thus, a cup for 'drink' or a spoon for 'dinner' should have a direct physical connection with the referent whereas a small piece of towel for 'swimming' does not. Secondly, it helps greatly if the referent is something the child really likes (e.g. a favourite toy or activity). Next, it must be easily accessible: for instance, when teaching that a plastic ball stands for 'ball pool', teaching should take place right next to the ball pool rather than in a classroom at some distance from it. Finally, the object has to have distinctive features which are likely to make it easy to recognise. It may help if each object has a distinctive smell or sound or feel which may be associated only with the referent.

The first step is to establish the idea of using an object to get a visible reward. Ockelford suggests that for some children making the connection may take many months of effort. Initially, there will be just one object close to the children and the associated reward will be in full view. Even so, children may need physical guidance to hand over, or otherwise indicate the object. The teacher then has to react as though they are intentionally communicating, say something like "You want the ", and give them their reward. This would continue until the children are consistently handing over or indicating the object to get their reward. During this time there may be frequent changes in the objects and rewards used as children's interest waxes and wanes, but there should only ever be one object and one reward used.

The next stage is to make sure that children understand that different objects have different meanings. This stage of discrimination learning can be a real stumbling block for many children and much depends on the teacher's skill and strategies. One possible strategy might be to introduce a second object that stands for something of no interest at all. In theory, children should come to realise eventually that handing over or indicating the wrong object will be followed by the non-preferred thing. When they consistently hand over the object for the preferred thing or activity, it is obvious that they are discriminating the two objects. Of course, if the second object represented another favourite thing or activity, there is no incentive to discriminate between the two objects: the children win whatever they hand over. Also, it would be impossible to tell whether they were responding deliberately or purely by

chance. The techniques for teaching discrimination learning requires much more research: Will certain colour, smell or tactile cues enhance the discrimination learning? Is the suggested strategy a sound one? What should be the balance between success and mistakes? Should physical prompts be used to reduce to almost nil the number of errors that children make?

Once the child is able to discriminate between two objects, a third object may be introduced that represents another preferred thing or activity. Again, there would have to be opportunities to discriminate between this object and the object which represents an uninteresting thing or activity. This is one possible way of teaching discriminative use of a range of objects of reference to communicate needs or preferences. Ockelford advises that, initially, objects should be chosen which are strongly contrasting in texture, shape and colour (if a child has vision) in order to facilitate discrimination learning.

Objects of reference may then be attached to special boards. Ockelford even suggests ways in which some items may be gradually cut down until they are small enough to be included in a portable book or folder. Much depends upon what the objects are. If they are attached by Velcro it may still be possible for the children to hand over objects to request things or activities, if they have the manipulative skills. This has the advantage of making it clearer to others what the children are asking for. However, for some children a pointing or looking response still remains the best method of communicating. Careful consideration has to be given to the verbal prompts that teachers use: What kind of questions may be used in particular situations?

Objects of reference offer exciting possibilities for communication with children with profound learning difficulties who have difficulties in interpreting two-dimensional representations such as pictures or photos. However, there has been almost no research into the use of objects for reference with children who do not intentionally communicate and some variation in practice is reported in the small amount of literature that exists. In particular, we need to understand better what factors are crucial in attaching to ordinary objects their special meaning as objects for reference. Keith Park suggests that there are real dangers in using rigidly standardised communication systems which use a particular set of objects to stand for or represent specific activities or things. It simply cannot be assumed that an apparently commonsense link between an object and the intended referent can be made obvious to each child. For instance, why should a cup stand for drink? Why not a squash bottle or a jug or a beaker instead? Standardisation in the use of objects of reference is not necessarily a wrong decision, but Park argues that children who are operating at a pre-intentional communication level need a communication system which is highly individualised and appropriate to their idiosyncratic understanding of their world. One child's set of objects simply may not be appropriate for another.

Park outlines a possible developmental framework for objects of reference in terms of the 'distance' between the objects of reference and their referents. A first step is to use a real object which is actually used in the activity (e.g. a cup identical to the one used for a drink). A next step could be to mount the object on a card so that there is a clear distinction the object of reference and the actual object (e.g. some raisins glued to a card and the raisins which will be eaten). Other types of objects of reference are at a somewhat greater distance from their referents: an associated object (e.g. a coin to represent 'shopping'); a partial object (e.g. the buckle from a seat belt to represent going on the bus); and an object with one or more shared features (e.g. a piece of vinyl material to represent 'soft play'). Truly arbitrary objects represent the most advanced and most demanding use of objects of reference as symbols (e.g. a wooden circle to represent 'yes'). Some use has also been made of miniatures of real objects (e.g. a small cup to represent 'drink'), but Ockelford and Park caution that a miniature may have little or no resemblance to the real thing for many children. Thus, using the buckle from a seat belt to represent 'going on the bus' may have much more meaning than a model of a minibus. The important step which requires more research concerns when and how to introduce more flexible picture-based or photo-systems instead.

There are other considerations besides in constructing a communication system, such as, the size of the objects, their arrangement and their accessibility. However, when choosing which early objects of reference to teach, the most important consideration relates to what Park calls the 'MMF principle',

where MMF stands for Meaningful, Motivating and Frequent. Are the objects of reference, and the concepts to which they refer, meaningful and relevant to that particular child? The next consideration when choosing which objects of reference to teach first is whether they relate to highly enjoyable activities or interesting things. Use of an object of reference by children should give access to an intensely rewarding activity or thing straightaway. What is motivating will vary from child to child. Painting or going for a walk may be a definite highlights in the day for one child; for another child the only things that really matter may be food or drink. Incidentally, Park queries why so many people are keen to establish an object of reference for 'toilet' in the early stages. Regrettably, many children with profound learning difficulties do not seem to be highly interested in the toilet and probably do not appreciate the benefits of remaining clean and dry. Therefore, 'toilet' should not be one of the first objects of reference to be taught, even though it is an important one to introduce at a later stage. The final consideration when choosing what to teach is whether there are frequent opportunities to establish the meaning of the object of reference. If swimming occurs only once a week, it is not going to be easy to assign a meaning to the object no matter how much the child enjoys swimming. However, if there is a daily romp in the ball pool, this object of reference may be a better one to teach in the early stages.

When the special meaning of objects for reference has been firmly established, a number of new developments may be pursued. One useful target would be to encourage decision-making. For instance, at snack time a choice of two objects may be offered representing two types of drink or a drink and a biscuit and each child encouraged to select one. Similarly, it may be possible to offer a choice of activity, such as, choosing the object for a particular song to be sung from a display of objects representing several songs. Lunchtime is another obvious time for making choices. Ockelford suggests that a next stage could be to gradually increase the amount of time between children indicating the object of reference and having access to its referent. This way it becomes possible eventually for them to request the 'ball pool' and be taken from the classroom to go to it. As long as the delay is not too long, it seems reasonable that children should learn that the things they want are not always instantly accessible.

Use of Objects for Reference in Timetables

Adam Ockelford also describes how it may be possible to develop children's anticipation of future events as a next step. Basically, the object of reference is presented by the teacher to children at the same time as, or followed quickly by, the relevant activity. Initially, the teacher works to make the children associate an object with a current activity, but, gradually lengthens the delay between the presentation of the object of reference and the start of the activity. Thus, the children learn that the presentation of an object of reference indicates that an activity is about to begin. The children have to get used to the fact that there may be a delay before the activity starts because it may be the case that the activity has to take place in a totally different part of the school (e.g. dinner in the dining hall, music in a music room).

Once this difficult hurdle has been crossed, it becomes possible to begin to teach children to anticipate temporal sequences of events by presenting their objects of reference in a spatial left-to-right sequence and talking about them: for instance, a ball and a cup placed in a left-to-right sequence could be used to indicate that "After the ball pool, you can have a drink". It is critical that this is taught in the context of well-established and frequently occurring routines. Even so, establishing anticipation of a next activity through use of objects of reference is not necessarily going to be easy. However, unless progress can be made at this level, there can be little value in introducing more than two objects of reference in timetables which indicate longer sequences of activities lasting for a whole morning or a day.

As regards children and young adults with visual impairments, Ockelford gives examples of the successful use of timetables. For one child, the timetable was made up with a series of boxes with an object of reference in each container. His timetable boxes have lids that can be closed to indicate that an activity is finished which makes it possible to regularly update the timetable and reduce confusion for the child about what comes next. Other approaches to creating timetables described by Keith Park

involve putting objects of reference in a line on a special shelf or putting them in compartments in a special box or drawer and with each change of activity the object of reference for the completed activity would be removed.

Park's MMF principle is still an important one even at this relatively advanced stage. Park notes with some concern that he has encountered some schools that use a separate object to denote each National Curriculum subject. In his view there is no justification for having these different objects of reference. There cannot be a meaningful distinction between the various National Curriculum subjects for pupils with profound learning difficulties. Thus, for many children it is sufficient to establish an object of reference which comes to represent 'sitting down with the others and doing something at the table with the teacher'. A simple gloss would be 'work' for the object of reference when it appears on the timetable. The same object could be used in relation to all work activities if it features in them all as a salient element, e.g. a small bell that is rung at the beginning of every session.

Final comments

This paper is a summary of the more accessible literature and provides an indication of what is known to work and issues which require further consideration by us all. All of us are using objects of reference successfully to some degree with children. They also have their applications in adult services. Collectively we are gaining much useful experience, but we are not doing enough to report our achievements and failures. The writings of Ockelford and Park raise many issues about good practice and they deserve to be widely read. It is hoped that readers will feel stimulated to report their experiences in PMLD-Link. Every contribution would be valuable.

Rob Ashdown, Headteacher at St. Luke's School, Scunthorpe

References for Further Reading

Ockelford, A. (1994) *Objects of Reference* London: RNIB (Revised edition)

Park, K. (1995) Using objects of reference: a review of the literature. *European Journal of Special Needs Education*, 10, (1), 40-46

Park, K. (1997) How do objects become objects of reference? *British Journal of Special Education*, 24 (3), 108-114

DEVELOPMENTAL MOVEMENT for CHILDREN

**By Veronica Sherbourne
(2nd Edition)**

A new edition of this classic text, with a new introduction, Resource List and with commentary from experienced practitioners who have been inspired by Veronica Sherbourne's work. The book shows how developmental movement plays a crucial role in the lives of children. Central to her theory is the belief that relating to oneself and other people are essential for the satisfactory development of us all. Gentle, Practical and accessible, and illustrated with more than 50 photographs, including several new ones.

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The following was sent out as a News Release by the Foundation for People with Learning Disabilities on publication of the White Paper 'Valuing People'.

**"Great White Paper, but is there the money to implement it?"
says Foundation for People with Learning Disabilities**

The Foundation for People with Learning Disabilities, part of the Mental Health Foundation, welcomes the learning disability White Paper, *Valuing People*, as a major opportunity to effect real change for a group of people whose needs have been neglected and overlooked, but is concerned that the available resources will limit action at local level.

The White Paper should go a long way to ensuring that the rights and choices of people with learning disabilities are, at last, listened to," said Hazel Morgan, head of Foundation for People with Learning Disabilities. "For example, its focus on the need for services to respond to the needs of older people with learning disabilities and those with dementia, and the urgent need to help people living with family carers over 70-years plan for the future is very welcome. Our Growing Older with Learning Disabilities programme has highlighted the numbers of people who are inappropriately placed in generic older people's services rather than services for people with learning disabilities, and the Government's recognition of this is crucial.

Valuing People also tackles a number of concerns raised in our recent report on making choice a reality for people with profound learning disabilities- *Everyday Lives, Everyday Choices* - such as direct payments, training and friendships. We still believe, however, that there should be a right to advocacy, and that further resources and attention should be paid to communication with people with severe learning disabilities.

But with services that have been underfunded for so long, and a huge unmet need for housing and day opportunities, for example, there is a substantial shortfall to overcome.

The new funds announced in the White Paper are less than one per cent of the annual spend on learning disabilities according to calculations from the Foundation for People with Learning Disabilities (see note 1), which in its recent report, *Learning Disabilities - the Fundamental Facts*, pointed out that:

Between 50% and 90% of people with learning disabilities experience communications difficulties but there is a great shortage of speech and language therapists with only 0.7 speech therapists per 100,000 population.

40% of people with learning disabilities living at home are living with family carers over the age of 60 years.

63% of adults with learning disabilities live in private households, most commonly with their natural families, but there is a widely acknowledged shortage of respite care services.

Only 10% of the working-aged population with learning disabilities are in supported employment.

"We welcome the extra resources, though limited, and the Government's focus on rights, independence, choice and inclusion - but if it is to work, local authorities and organisations must seize this moment to take a radical look at the support and opportunities they provide," said Hazel Morgan. "This means listening closely to people with learning disabilities and their carers in implementing *Valuing People*. Only then will the young woman with profound learning disabilities, for example, be supported in making real choices about the way she spends her days."

Editor's notes

1. The current annual budget for learning disability services is £3bn, as quoted in the White Paper, *Valuing People*. The White Paper announced a £50m development fund, of which £30m is existing

revenue which had been previously allocated to long-stay hospitals, together with an implementation and support fund of £2.3m and a further £2m for a research initiative. The £24.3m new money is less than one per cent of current annual budget. If the £30m existing revenue is included as new funds then this is still less than two per cent additional funding.

The Foundation for People with Learning Disabilities works to improve the lives of people with learning disabilities through:

- Funding innovative research and service development projects and disseminating findings
- Listening to people with learning disabilities and involving them in its work
- Seeking to influence policy
- Providing specific and appropriate information to people with learning disabilities

Launched in October 1998, it is part of the Mental Health Foundation, which has been working with people with mental health problems and people with learning disabilities for over 50 years.

Further information:

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letters..... and e-mails

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"In the last issue I wrote asking for ideas to adapt the curriculum for my son Juan. He has severe multiple disabilities and was starting his experience in a mainstream school. As you may know this is extremely unusual in Argentina. Special and mainstream teachers and headmasters and the family form a team that, while providing for Juan's needs, try to record the experience to serve as a model.

Fortunately I learnt about the *Curriculum Guidelines: Planning, Teaching and Assessing the Curriculum for Pupils with Learning Disabilities* for the British National Curriculum. They are of extremely great value for us. They provide those things that you need to know when you have to plan for a child and at the same time have the plan accepted by the authorities. And it adapts perfectly to the curriculum of our mainstream schools.

Thank you very much to all the people that have worked in these Guidelines and to the authorities that make it available for all the public.

Elena

report back

MENCAP PIMD SEMINAR SERIES: Curriculum Guidelines for Pupils with Severe and Profound Multiple Learning Difficulties: QCA Research Project

This seminar was held on Tuesday 27th February 2001 at the MENCAP offices in Birmingham. Dr. Christina Tilstone who led the project team which produced the *Curriculum Guidelines for Pupils Attaining Significantly Below Age-related Expectations* gave an overview of all aspects of the preparation of this publication.

Introduction to the project

The Qualifications and Curriculum Authority (QCA) Brief

To develop an inclusive curriculum for children achieving significantly below age related expectations, between 5-16 years old, who would not achieve above level 2 of the National Curriculum. The project is aimed at children in the PMLD/ SLD range and for those with a 'bumpy profile' i.e. performing better in some areas than others.

A collaborative approach

The QCA put out information on the project and held a briefing session. The participating organisations decided that the project was too complex for any one of them to undertake in isolation and decided to collaborate, rather than bid against one another. This led to the project becoming one of the biggest collaborative events of its kind. A number of organisations were directly involved.

Who is Involved?

The University of Birmingham School of Education

Christina Tilstone

The University of Cambridge School of Education

Richard Byers

The School of Social Sciences Cardiff University
(On secondment to St Patrick's College, Dublin)

Jean Ware

EQUALs Project Team Representative

Michael Thompson

In addition there have been wide ranging formal and informal consultations. These have been with practitioners who could look across the subject areas, consultants who looked across the curriculum, critical friends who challenged ideas and helped to break new ground, and specialists. QCA subject specialists were also involved in specific areas. This proved to be a valuable relationship and one which will pave the way for future work with the QCA.

The relationship with OFSTED was an important one as they will ultimately approve and inspect the curriculum, and a rewarding part of the process in which they supported some radical ideas such as the allocation of time for the therapies.

Approach to developing the Curriculum

The QCA stated that the Guidelines must:

- Set out clear learning outcomes with provision for lateral and vertical progression; this acknowledges that some children with severe and profound learning difficulties will be working on some targets across the different subject areas for all their school lives.
- Acknowledge the widening experience of pupils as they move through education; a choice had to be made here between selecting a 'developmental' curriculum or to mirror the National Curriculum and use the subjects as a context for learning. The project team felt that a developmental approach was too narrow and in consultation with the field, opted for the subject based curriculum.
- Present learning opportunities in age appropriate contexts; there was a balance to be struck here between the pupils' stage of development as well as their age.

The agreed outcomes must be to produce:

- Guidance on how the materials are to be used;
- Supplementary material to the programmes of study for all national curriculum subjects in all appropriate key stages;
- Supplementary curriculum materials for other areas of the whole curriculum (such as personal, social and health education, and religious education) in all four key stages;
- Descriptions of attainment for each subject area, showing progress and achievement from the earliest stages leading up to level 1;
- An interpretation of the key skill categories and other priority skills for pupils with learning difficulties;
- Guidance on the development of the whole curriculum for pupils with learning difficulties.

A framework for recognising attainment

The framework below was drawn up from research evidence and the influential work of other researchers. Within every single subject within the curriculum this framework has been used.

Encounter: Pupils are present during an experience or activity without any obvious learning outcome, although for some pupils, for example those who withhold their attention or their presence from many situations, their willingness to tolerate a shared activity.

Awareness: Pupils appear to show awareness that something has happened and notice, fleetingly focus on or attend to, an object, event or person, for example, by briefly interrupting a pattern of self-absorbed movement or vocalisation.

Attention and response: Pupils attend and begin to respond, often not consistently, to what is happening, for example, by showing signs of surprise, enjoyment, frustration or dissatisfaction, demonstrating the beginning of an ability to distinguish between different people, objects, events and places.

Engagement: Pupils show more consistent attention to, and can tell the difference between, specific events in their surroundings, for example, by focused looking or listening; turning to locate objects, events or people; following moving objects and events through movements of their eyes, head or other body parts.

Participation: Pupils engage in sharing, taking turns and the anticipation of familiar sequences of events, for example, by smiling, vocalising or showing other signs of excitement, although these responses may be supported by staff or other pupils

Involvement: Pupils actively strive to reach out, join in or comment in some way on the activity itself or on the actions or responses of the other pupils, for example, by making exploratory hand and arm movements; seeking eye contact with staff or other pupils; or by speaking, signing or gesturing.

Gaining skills and understanding: Pupils gain, strengthen or make general use of their skills, knowledge, concepts or understanding that relate to their experience of the curriculum. For example, they can recognise the features of an object and understand its relevance, significance and use.

The framework moves through from 'encounter' where pupils may be present during an activity without any obvious learning outcome, 'awareness', 'attention and response', 'engagement', 'participation', 'involvement' to the level of 'gaining skills and understanding' in which 'pupils gain, strengthen or make general use of their skills, knowledge, concepts or understanding that relate to their experiences of the curriculum'. The curriculum becomes more subject specific at P levels 4-8.

The phases of developing the Curriculum

Phase one: October to December 1999

In addition to the appointment of three research officers, there was considerable collaboration with practitioners.

Key activities:

- The appointment of two part-time research and development officers.
- Collaboration with practitioners in order to reach an agreement on the content of the guidelines.
- The appointment of a third research and development officer together with 12 practitioner researchers (to commence work in January).
- The production of a range of papers dealing with topics relating specifically to the teaching and learning of pupils with learning difficulties.

Phase two: January to March 2000

During this phase the team wrote to over 700 schools to assemble the teams of practitioners who would work on the specific sets of materials under the guidance of the development officers. 38 people applied and 9 were appointed after rigorous selection criteria were applied. The participants would need specific skills and they would also need to be released by head-teachers to do the work.

Key activities:

- Three teams of practitioners (four in each team) in different parts of England to develop specific sets of materials under the guidance of the research and development officers.
- The core project team to meet on a regular basis.
- Emerging materials were subjected to ongoing comment, evaluation and review. The work on the prose sections of the guidance was to be continued.
- The core project team consulted, and collaborated with, critical friends and practitioners.

Phase Three: March to May 2000

During this phase there were informal and wide ranging consultations and the framework kept altering. Finally consultation documents were sent to 440 schools. There was a huge response with the overall one being that the framework was one that people had been waiting for. Teachers also wanted the guidelines linked to schemes of work.

Key activities:

- The development teams completed their work.
- Informal wide ranging consultation proceeded on the completed drafts of materials.

Phase Four: May to July 2000

Further random and independent consultation took place on the draft materials.

Key activities

- Dr Jean Ware has undertaken a wide random consultation on the drafts of materials.
- The guidelines have been scrutinised by critical friends and consultants.
- The core project team to revise the guidelines.

Phase Five: July to August

Key activities

- In the light of the analysis of the data, the core team worked on the final revisions to the guidelines.
- Further consultations with the subject specialists have been undertaken.

The content of the guidelines:

There are three components:

- Booklet on developing and planning the curriculum (General guidelines)
- Booklet on developing skills across the curriculum
- Booklet on planning and teaching each National Curriculum subject, religious education and PSHE.

All have a framework for assessment.

Content of General Guidelines:

- Determining the curriculum for your school
- Planning the curriculum
- Recognising progress and achievement
- Planning for change: Monitoring, evaluation and review

Subject Booklets:

Provide guidance on:

- The importance of the subject area
- Ways of modifying the statutory requirements
- Age-related activities and opportunities
- Performance descriptions

Key Skills:

- Communication
- Application of number
- Use of information and communication technology
- Working with others
- Improving own learning and performance
- Problem solving
- Thinking Skills

Other priority skills:

- Physical, orientation and mobility skills
- Skills for learning disability
- Organisation and study skills
- Personal and social skills
- Personal care skills
- Managing own behaviour
- Managing own emotions
- Daily living skills
- Domestic skills
- Community skills

Planning for Progression for Individuals or Groups might focus on:

Skill Development: Where pupils are encouraged to gain new skills; to practice, maintain, combine, develop, refine transfer or generalise existing skills; or to reactivate skills gained previously, for example, a pupil who has learned to work with numbers up to 10 by the end of key stage 3 may be taught to develop those skills in vocational activities in key stage 4 and post-16.

Breadth of curricular content: In order that pupils' access to new knowledge and understanding is extended, for example, teaching all pupils about the biological aspects of adolescence and adulthood at key stage 3.

A range of contexts for learning: In which pupils are offered a variety of activities, resources and environments appropriate to their age, interests and prior achievements, for example, encouraging pupils to use their senses to explore events and environments beyond the specialist sensory room.

A variety of support equipment: To enable pupils to take control of their environment; to increase mobility; to develop and practice communication skills, for example, a pupil who has learned to make choices using a computer programme might be offered greater autonomy by using a communication device to say what they want to do or to initiate interactions with others at key points in the school day.

A range of teaching methods: Determined by pupils' individual strengths and learning styles at different stages of development, for example, promoting increasing cooperation between pupils and a reduction in the need for staff support.

Negotiated learning: Where pupils are encouraged to take a greater part in the learning process, and in planning or measuring success, for example, pupils help to make their record of achievement or progress file and select work they consider their best, as well as setting personal goals.

Application of skills, knowledge and understanding in new settings: Where pupils are offered learning opportunities in specialist, mainstream and community environments, for example, encouraging older pupils to apply their developing numeracy skills in community rather than classroom settings.

Strategies for independence: Where pupils are helped to move away from adult support and class-based activities towards autonomy and self-advocacy in the community to prepare for life beyond school, for example, pupils in key stage 4 or post-16 provision might use arts or food technology facilities at the local sixth form or further education college and work with their fellow students in a vocational setting.

Conclusion:

The work is innovative. The guidelines have been developed by building on good practice and the principles of inclusion set out in the National Curriculum and are designed to help schools develop an inclusive curriculum. The materials are, however, broader than the subjects of the National Curriculum and cover aspects of the whole curriculum. The work it describes is based on some of the good practice well developed approaches that have been developed by teachers and specialists in the field. What it does, is to give a clear framework and validity to that work. Material which has not been used in the document may appear on the web at a later date.

Beverley Dawkins
PMLD-Link Editorial Group
National PIMD Officer for MENCAP

FUTURE FOCUS - Parents' Forum

This next edition of PMLD-Link must be of interest to anyone who has any dealings at all with people who have a learning disability. The involvement of parents and family carers with the professional agencies, support groups and charities is essential and all involved must have their opinion and experiences of such interactions.

My wife and I are parents of a daughter who has a severe learning disability coupled with challenging behaviour. She is 29 years old and spends some of her time at a care home that we own. This puts us in the unusual, but by no means unique category of being both a parent and service provider. We deal with all of the professionals in the wide variety of disciplines that engage on a day to day basis with our clients at the care home and our daughter. In her case we do this both in the context of her as a client of the care home and as our daughter.

Over the course of the years of being a parent it has become clear that, while invariably well intentioned, the professional, in whatever discipline, does not know your child as well as you do - even though they may think they do! This does not mean however that there are not times when they know what is best. Unfortunately they may not always put this across as well as they might and certainly do not always give the impression of hearing, let alone listening to your opinion as the parent of their client. Indeed some can be aloof to the point of pomposity and arrogance.

I have been fortunate enough to be allowed to take part in an educational course on interdisciplinary co-operation within the field of learning disabilities. This gave me an invaluable insight into how things can work when the professionals discuss your child. There is a danger that parents and their views can be completely lost in the general melee. This confirmed my experience as a parent that you must stand your ground and sometimes shout to make sure that your voice is not only heard, but also listened to if you and your child are to receive the support that you want and need.

Of course, professionals have a job to do and I know from experience that parents can be a hindrance and on occasion part of, if not all of the problem. Properly included however, parents can be an asset and must always be considered and involved fully in any situation. It is imperative that everyone involved in dealing with the requirements of someone with a learning disability act as far as is possible with one aim - the benefit of that person. This includes both professionals and parents, who must respect and try to understand each other's opinion and viewpoint, trying to take the best from each others input.

Other than the support and help which we have had from the professional sector, we have, over the years had involvement with our local carers' support group and Mencap. These have given us strength and confidence at times of need and uncertainty when each day brought a new challenge as our daughter grew and developed.

That is my experience. What is yours? The next issue is hoped to be a forum for the views of parents and carers - where your voice can be heard. Have you hit the brick wall of professional deafness? How did you deal with the situation? Have you developed any innovative strategies to deal with this or other day to day difficulties that have been adopted within your family or group? Have you had any really positive experiences which may be a ray of hope for other parents or be a pointer for other practitioners and carers? Please write about your experiences and views for the next edition of PMLD-Link.

Steve Simmonds
PMLD-Link Editorial Group

reviews ... reviews ... reviews ... reviews

A Practical Guide to Intensive Interaction

by Melanie Nind & Dave Hewett
Published by BILD (2000)
Price £16.00 ISBN 1 902 519 63 9

I just can't smother the comparison. I have tried reasoning that it's highly irrelevant to the subject matter and probably 'unprofessional' but here we go.

A practical Guide to Intensive Interaction is like seeing the film of Captain Correlli's Mandolin after reading the book. Films are a brilliant way of sharing a subject matter with a mate who isn't into reading.

Personally I'm relieved that 'A Practical Guide to Intensive Interaction' didn't come out before Access to Communication or I would have been sorely tempted to miss a most pleasurable anti-social weekend (still managed to go to my local - just kept telling everyone to go away!).

A practicable Guide to Intensive Interaction is just that - highly accessible. Its light touch may well appeal to those who wouldn't usually read a work-related book - the cartoons help!

This book should appeal to anyone involved (or thinking of becoming involved) in the delivery of Intensive Interaction. It's a quick read and a very useful 'dip into' book for specific advice.

Particularly useful is the advice about where to go when Intensive Interaction has worked - I suspect more on this subject would be very welcome.

A good book that is an essential addition to reading resources for those who work with people with Profound Learning Disabilities.

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Teaching Children who are Deafblind

Aitken, S, Buultjens, M, Clark, C, Eyre, J. & Pease, L. (ed.)
David Fulton Publishers (2000) 256pp
Paperback £18.00 ISBN 85346 674 3

This book will be welcomed by professionals working with pupils who are deafblind or have multisensory impairments. In an era when there is growing awareness of the incidence of deafblindness there is an

expanding need for those working with deafblind pupils to understand and utilise specialised approaches enabling their pupils to access their world and receive appropriate education.

It provides a comprehensive coverage of the subject including the creation of a communicating environment, curriculum issues (both in England and Wales, and in Scotland), and effective teaching and learning styles. Effective ways of working with parents and other agencies are explored: the important issues of challenging behaviour and use of restraint are addressed along with relevant legal aspects. The book also includes a useful glossary of terms and a further reading list.

Communication is given due prominence, both in creating a communicating environment for pupils, and the need for those working in this field, including parents and other agencies, to be good communicators. Strategies are included for both of these elements with due emphasis being put on creating total communication environments for deafblind children.

The book refers to both the National Curriculum and the P scales. It highlights the need for further work to be undertaken by teachers in order for these to be accessed by deafblind pupils and the need for those who put these descriptors together to recognise and address the possible implications of a sensory loss. Those working in this field in Scotland will be pleased to find that part of the chapter on curricular frameworks includes the Scottish context, drawing out the merits and challenges of a less prescriptive and more flexible system that regards teachers as independent and responsible professionals.

The challenges posed by the need for, and the cost of providing appropriate staff training are voiced, stressing the increasing need to train the growing army of support staff who are working with deafblind pupils, particularly if and when the move to greater inclusion comes.

This book addresses the needs of a very specialised minority of pupils and provides accessible, succinct and pertinent reading for those working with them. Many of the issues explored in this book are relevant to those working with individuals with PMLD, who function as or are known to have a dual sensory loss. This book will have most appeal to those in school settings or are undertaking study in this field.

Jill Wilson

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***Supporting Literacy and Numeracy.
A guide for Learning Support Assistants***

Glenys Fox and Marian Halliwell
Published by David Fulton (2000)
ISBN 1-85346-679-4 112 pages
Paperback £13.00

Although this book is aimed primarily at Learning Support Assistants (LSAs) in mainstream schools it contains a lot of information which is relevant to LSAs working with pupils with SLD/PMLD. It emphasises the important issues such working in partnership with teachers and parents and the need to keep confidences. Certainly the section on the qualities needed to be an effective LSA is relevant to all LSAs. It is also important that LSAs know the theory of how children learn in order to be able to identify areas in which the children, with which they work, are experiencing difficulties.

The book contains concise and clear sections on teaching and learning styles and also considers what may be happening to stop a child from learning and how these might be overcome. In the section on reading awareness the authors highlight the value of multi-sensory techniques, an approach that can be particularly valuable for pupils with SLD/PMLD. Although useful as underpinning knowledge, the section on writing is of less value in the practical

sense; it does however refer to the use of ICT, which can be of enormous value to pupils with SLD/PMLD.

The chapter on Numeracy skills highlights the way in which language plays an essential part in the development of Numeracy and mathematical skills. It draws the reader's attention to the difficulties a pupil with dyslexia may be facing and some ideas about overcoming these.

The book is a useful tool in the induction and continuing professional development of LSAs. The format and design of the book makes it very accessible and understandable. This makes it a useful addition to school libraries for their staff. Although there are parts of the book which do not relate directly to the work situation LSAs might find themselves in, in a school for pupils with SLD/PMLD it does set the context of both the Literacy and Numeracy strategies. It is important for all staff working in the field of SLD/PMLD to maintain a clear picture of what is happening in mainstream schools in order to set their own work in context.

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NEW BOOKS AND RESOURCES

The Education and Care of Children with Severe, Profound and Multiple Learning Difficulties by R. Aird, published by David Fulton (2000) ISBN 1 853346 708 1

Developmental Movement for Children by Veronica Sherbourne (2nd Edition) with new introduction and resources, published by Worth Publishing Ltd. (2001) ISBN 1 903269 04 0

Baseline Assessment, Curriculum and Target Setting for Pupils with Profound and Multiple Learning Difficulties by Sonia Maskell and Fran Watkins published by David Fulton (2001). ISBN 1 85346 690 5

Activities for Older People: A practical workbook of art and craft projects by Brian Banks, published by Butterworth Heinemann (2000) ISBN 0 7506 4741 8

A Sensory Approach to the Curriculum by Judy Davis, published by David Fulton (2001) ISBN 1 85346 671 9

The Team Around the Child: Multi-agency service coordination for children with complex needs and their families by Peter Limbrick published by and available from Interconnections 15 Haversham Court, Middleton Road, Manchester M8 4JY ISBN 0 95409976 0 2

Communication, Curriculum and Classroom Practice by Clare Latham and Ann Miles, published by David Fulton (2001) ISBN 1 83546 732 4

Fragile X Syndrome. A Guide for Teachers by S. Saunders, published by David Fulton (2001) ISBN 1 85346 536 4

See What I mean by N. Grove, K. Bunning, J. Porter and M. Morgan, published by BILD (2000)
ISBN 1 902519 41 8

Approaches to Teaching and Learning: Including Pupils with Learning Difficulties by R. Babbage, R. Byers and H. Redding in association with St. John's School, Kempston and published by David Fulton (2001)
ISBN 1 85346 575 5

Babies and children with Prader-Willi Syndrome - a handbook for parents and carers by Jackie Waters and Margaret Gellatly, published by PWSA(UK), 33 Leopold Street, Derby DE1 2HF

A Framework for Learning by Caroline Allen, published by David Fulton (2001)
ISBN 1 85346 760 X

All About Autistic Spectrum Disorders produced by and available from Foundation for People with Learning Disabilities: 020 7535 7422 or email Lwarner@mhf.org.uk

Towards a Curriculum for All: a Practical Guide for Developing an Inclusive Curriculum for Pupils Attaining Significantly Below Age-Related Expectations written by the Dorchester Curriculum Group, published by David Fulton (2001)
ISBN 1 85346 773 1

Mathematics for Children with Severe and Profound Learning Difficulties by L. Staves, published by David Fulton (2001)
ISBN 1 85346 695 6

Using a Multisensory Environment: A Practical Guide for Teachers by Paul Pagliano, published by David Fulton (2001)
ISBN 1 85346 716 2

CaF Holiday Factsheet leaflet produced by CaF and available from CaF West Midlands Tel. 0121 455 0655 or on the website www.cafamily.org.uk

Books reviewed in this issue

A Practical Guide to Invasive Interaction by Melanie Nind and Dave Hewett, published by BILD

Teaching Children who are Deafblind edited by S. Aitken, M. Buultjens, C. Clark, J. Eyre, and L. Pease, published by David Fulton

Supporting Literacy and Numeracy. A guide for Learning Support Assistants by Glenys Fox and Marian Halliwell, published by David Fulton

COURSES AND CONFERENCES

SEPTEMBER

- 10th to 12th BILD 2001 International Conference
Equalising Opportunities for People with Learning Disabilities.
 Themes will include: obstacles to inclusion; lifelong learning; education; equal opportunities for vulnerable adults; specialised v. mainstream services; civil rights/human rights; needs-led services; what is best practice; challenging behaviour.
 Organised by: BILD
 Venue: Cork, Ireland
 Further details: Liz Howells
 BILD, Wolverhampton Road,
 Kidderminster, Worcs DY10 3PP
- 28th History and Geography for pupils with Severe/Profound and Multiple Learning Disability
 Issues related to planning and teaching history and geography with a central theme of access. The programmes of study for history and geography will be considered in light of the curriculum guidance issued in March.
 Organised by: Sunfield Professional Development Centre
 Led by: Clare Martin
 Venue: Sunfield Professional Development Centre, Stourbridge
 Further details: Jackie Wadlow
 Tel. 01562 883183
 email: Sunfield@sunfield.worcs.sch.uk

OCTOBER

- 5th to 7th Sherborne Association Course - Level 3
 This 3 day residential course is for advanced practitioners and aims to extend participants' skill-base through a deepening awareness of SDM theory, philosophy, psychological aspects and application in various fields, e.g the arts and therapy
 Organised by: Sherborne Association
 Venue: Heathermount
 Further details: Stephanie Lord
 Tel: 01344 875101
- 9th Assessing the progress of pupils with learning difficulties
 Consideration of ways in which the assessment of progress and progression of pupils with learning difficulties can be undertaken in relation to the new QCA materials *Planning Teaching and Assessing the Curriculum for Pupils with Learning Difficulties*. An opportunity for staff of schools to share problems and solutions.
 Organised by: Sunfield Professional Development Centre
 Led by: Dr. Christina Tilstone
 Venue: Sunfield Professional Development Centre, Stourbridge
 Further details: Jackie Wadlow
 Tel. 01562 883183
 email: Sunfield@sunfield.worcs.sch.uk
- 16th Focusing on the Family:
 A one day conference sharing practical information about co-ordinated multi-agency work with families who have a child with complex disabilities/special needs. Designed for managers and practioners in health, education and social services; parents and carers; workers from the voluntary and independent sectors. Sessions will feature good practice in keyworking, the team around the child and multi-agency child development centres.
 Organised by: Handsel Trust
 Venue: City Hospital, Birmingham
 Further details: Peter Limbrick
 Handsel Trust, 15 Haversham Court
 Middleton Road, Manchester M8 4JY
 Tel. 01161 740 7757
 p.limbrick@u.genie.co.uk

29th Assessment in the curriculum for pupils with severe learning difficulties
 This course will explore the relationship between assessment for individual pupil's needs within a whole curriculum context and how pupils' learning priorities may be identified with ways to incorporate these alongside assessment of achievement and attainment.
 Organised by: Sunfield Professional Development Centre
 Led by: Dr. Richard Rose
 Venue: Sunfield Professional Development Centre, Stourbridge
 Further details: Jackie Wadlow
 Tel. 01562 883183
 email: Sunfield@sunfield.worcs.sch.uk

NOVEMBER

6th Supporting Learners with SLD and PMLD with Clicker 4, Intellitools, and Powerpoint
 to On this three day course participants will be shown how to develop their own solutions
 8th for their learners using these systems. Best practice will be highlighted.
 Day 1 - Clicker 4; Day 2 - Intellikeys; Day 3 - Powerpoint.
 Organised by: Liberator
 Led by: Tony Jones and Martyn Maltby
 (both practicing teachers working with young people with PMLD)
 Venue: Liberator Ltd, Lincs
 Further details: Alison at Liberator
 Whitegates, Swinstead, Lincs NG33 4PA
 Tel: 014 76 550 391
 Sales@liberator.co.uk

9th Epilepsy and Rectal Diazepam Awareness Training
 This day's training aims to provide staff with an understanding of how to administer emergency treatment to an individual with epilepsy. The course is designed for nursing staff and carers. The training will include workshops, videos and practical demonstration. The British Epilepsy Association supports this course.
 Organised by: Sunfield Professional Development Centre
 Led by: Louise McMichael
 Venue: Sunfield Professional Development Centre, Stourbridge
 Further details: Jackie Wadlow
 Tel. 01562 883183
 email: Sunfield@sunfield.worcs.sch.uk

15th Families Together
 Speakers will cover topics including Recent research on family support needs, Commissioning and providing services for people with PMLD; Developing support services. A choice of five afternoon workshops.
 Organised by: MENCAP/Pavillion
 Speakers/leaders: Prof. James Hogg, Loretto Lambe, Prof. Barry Carpenter, Helen Sanderson; Rosie Rowland, Dr. Tricia Sloper, Christine Lenehan, Nadine Jay
 Venue: London Voluntary Services Resource Centre
 Further details: Mencap, 123 Golden Lane, London EC1
 Tel. 0207 454 0454

16th Sherborne Developmental Movement - Level 1
 Organised by: Sherborne Association
 Venue: Heathermount
 Further details: Stephanie Lord
 Tel: 01344 875101

17th Enabling Access Conference
 A Conference to discuss the implications of the new National Curriculum, and subsequent guidance, for pupils with learning difficulties.
 Organised by: Sunfield Professional Development Centre
 Speakers: Dr. Christina Tilstone
 Dr. Phillippa Russell
 Venue: Sunfield Professional Development Centre, Stourbridge
 Further details: Jackie Wadlow
 Tel. 01562 883183
 email: Sunfield@sunfield.worcs.sch.uk

OPEN DAYS

Action for Leisure Resource Centre Open Days:

Low cost Multisensory Room; Wide selection of toys, games and equipment; Small items to purchase; Database of information; Reference library of books, videos, journals and publications; College farm animals; Garden centre.

Refreshments; disabled toilet on site; parking space for disabled drivers

Open between 9.30 am - 12.30pm or 1.00 pm - 4.00pm.

25th July	9th October
9th August	22nd October
24th August	7th November
6th September	19th November
18th September	1st December
29th September	

Booking form from:

Action for Leisure, C/o Warwickshire College, Moreton Morrell, Warks CV35 9BL

Tel: 01926 650195

www.actionforleisure.org.uk

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

University of Birmingham School of Education

Further details: Sandra Cumberworth, 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: Helen Bradley Tel: 0121 678 2353

Profound Learning Disability and Multi Sensory Impairments

A two year course for parents, carers and professionals which will develop skills and obtain recognition for them. Work is home based, supported by workshops and telephone tutor support. Issues relating to challenging behaviour, communication, education, ordinary life principles, sensory impairment, interdisciplinary working and epilepsy are addressed.

The course is offered at three levels: Certificate, Advanced Diploma and Masters.

University of Manchester Faculty of Education

Further details: The Programme Secretary, Educational Support & Inclusion,
 University of Manchester, Oxford Road, Manchester M13 9PL

Tel. 0161 275 3337

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