

# PMILD



# LINK

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

**Summer 2005**

**Families**

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

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

Views expressed by contributors to PMLD Link are their own and do not necessarily reflect the policies and opinions of the editorial team

# GUEST EDITORIAL

## Summer 2005

### Families

This issue has a focus on 'Families'. We have been overwhelmed, not only by the number of articles, but the calibre of the contributions. They are outstanding, and full of valuable insights. I am sure that readers will find much of relevance in each piece.

Twenty years ago, from an HMI-led conference on profound and multiple learning difficulties at Westhill College, Birmingham, *PMLD-Link* was born. It was my pleasure to act as the founding editor, eventually handing over to Carol Ouvry, whose diligent stewardship has made *PMLD-Link* the success that it is.

Now I have the opportunity to act as guest editor, and I am amazed how far we have come since those 'cut and paste' days of preparing each issue. The progress in the education and care of children and adults with PMLD is also obvious from the quality of the articles received.

This seems an appropriate juncture for me to bow out of the Editorial Group, wishing all of my colleagues every success as they take *PMLD-Link* forward. The need to advocate is as strong as ever. *PMLD-Link* is a powerful voice. I, for one, am proud of all it has achieved over the last 20 years.

With good wishes to you all for the excellent work you do.



**Barry Carpenter**  
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## Future Focus: Meaningful Involvement

By Rob Ashdown

The original suggestion of a theme for the Winter edition was 'Inclusion'. However, this much-used word still has so many different meanings for people despite, or perhaps because of, the plethora of books and articles on the topic. Also, there is still a tendency for 'inclusion' to be used in relation to educational provision, and the editors for PMLD Link always like to have contributions, not just from educationists and school staff, but also from parents, carers and professionals working for the various statutory agencies and voluntary bodies.

We tried to think of alternative titles which might grab everybody's interest, and we came up with the word 'Involvement' after examining several possibilities. The word actually does imply close relationships and the fact that people are an essential part of an activity or process. The word is also used to denote the enthusiasm that a person feels when they are taking part in something that they care deeply about. So the word works well for our purposes on several levels. It reflects the principle that the opportunity for involvement in the ordinary life of the family, the local community and the wider world is a fundamental human right.

'Meaningful' is also an important adjective that works on several levels. The use of the word should make plain that we want to print details about attempts to involve people with profound and multiple learning difficulties that are important emotionally and intellectually to all and that for all people involved are understandable and make sense.

We know that there are many stimulating examples out there of the meaningful involvement of children and adults with profound and multiple learning difficulties. We have heard anecdotes from parents, siblings, other care givers, teachers, social workers, support workers, nurses, further education lecturers and many others. We have heard of ways of involving people in making choices about their learning and living; of interesting projects that have aimed to involve people in their local community; and of people that are fully involved in the lives of their families. We want to know what strategies have worked well. Also, we appreciate that achieving meaningful involvement is a hard struggle, and it is worthwhile knowing about what has not worked so well and why. So please put your ideas and experiences down on paper. We look forward to your contributions, however brief.



Rob Ashdown (Guest Editor: Winter Edition on 'Meaningful Involvement')  
Head Teacher, St Luke's Primary School, Scunthorpe, North Lincolnshire

## Helping Families of Very Young Children with Disabilities: National Developments

By Barry Carpenter  
*Chief Executive, Sunfield*

*Our lives fell into a black fog – this news that our baby had a disability. They called it a diagnosis. For us, it was like a stab in the heart; your whole body filled with searing pain. Then hoards of professionals entered our lives – people with titles we had never heard of. This was not how it was meant to be, our lives, our little family, controlled and directed by others.*

These are the words of a father some weeks after his son was diagnosed with a rare genetic abnormality. His experience reflects that of many parents at the time of diagnosis of their child's disability, whether the diagnosis was made at birth, weeks later, or indeed 18 months–2 years or more afterwards (often even later in the cases of children with autistic spectrum disorders).

'Early Intervention' (anything which supports a child's development, from family support to therapy and health care, between 0 and 3 years) is now recognised as the hand that guides families through the 'life in a fog' experience that so many parents describe. This will be one of many issues discussed on 28 and 29 November this year when a European Early Childhood Intervention Conference will be held at the International Convention Centre, Birmingham. Speakers will be provided by the European Association on Early Intervention, including Dr Patricia Champion from New Zealand, and Dr Michael Guralnick from the USA, who is President of the International Society on Early Intervention.

So how does Early Intervention work? Although some families have positive experiences, services for most families are dependent upon a 'postcode lottery'. Sadly, the UK has lacked a national co-ordinated strategy for Early Intervention, and there has been no real policy focus on this most vulnerable time in the family's life, when their child has been newly diagnosed with a disability.

Less than 10 years ago, a European Union study revealed that the UK was the only EU

member country not to have a national policy in this area. Without this national direction, Early Intervention Services were fragmented, leaving many families feeling abandoned, and looking for the support that is so desperately needed for them and their child with special needs.

At long last, we are beginning to see some very encouraging changes happening with the launch of the Early Support Programme which is now being rolled out in every region. The programme offers immediate, high quality information to families, and advocates a keyworker approach. The keyworker is identified by the family, usually from within the team of professionals supporting them, as the person whom they would like to take the lead on the support offered to them. The Family Service Plan puts the focus on the family, as the key stakeholder in their child's life, and, in doing so, empowers them, helping them feel in control.

Combined with the SureStart programme (which is already having a major impact for many families in areas of social deprivation), the Early Support Programme is the Government's major approach to eradicating child poverty in the UK by 2020.

Another exciting initiative is the possibility of a National Centre for Early Childhood Intervention, which would act as a hub of information for families, stimulate high quality training for professionals, and give evidence-based advice to Government and other national bodies.

With these developments in Early Intervention at a national level, at long last there is a very real opportunity for families of very young children with disabilities to get immediate help, making a huge difference to the lives of these vulnerable families, a difference that as a respectable society we can be proud of!

Twenty years ago, when our daughter with Down's syndrome was young, my wife and I struggled to find empathetic professionals who could help to 'lift the fog'. The real prospects for Early Intervention, for families and for the children, need to be seized with enthusiasm and implemented with vigour. Together we can make a difference.

**Further information about the European**

**Conference on Early Childhood Intervention can be obtained from Rose Welling, Training Administrator, Sunfield Professional Development Centre (Tel: 01562 883183; Email: [Rosew@sunfield.worcs.sch.uk](mailto:Rosew@sunfield.worcs.sch.uk)) or from the website ([www.sunfield-school.org.uk/eci/conference.htm](http://www.sunfield-school.org.uk/eci/conference.htm)).**

**A families pack, entitled 'Talking to families; listening to families', edited by Barry Carpenter with a foreword by Philippa Russell (Special Policy Adviser on Disability for the National Children's Bureau), containing articles on working with families, is available from Sunfield (price: £8.50).**

## Check The Map

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- ◆ If you work with or for people with Learning Disabilities, this site is invaluable for you and all your colleagues – please spread the word!
- ◆ Promote the wonderful work that you do – it's easy, takes seconds and best of all it's FREE
- ◆ You'll find ALL your local and national services, events and resources – everything, across every sector
- ◆ Everybody gets equal promotion, no matter what the size or scope of their project or organisation

## 'Parent of a Disabled Child' – Would You Apply for this Job?

By Gail Hanrahan

My son, Guy, was diagnosed with a rare chromosome disorder called Angelman syndrome in 1991 when he was 15 months old. I can remember at the time being given certain articles by well-meaning people. You may have seen them. They usually began: 'God looked down from Heaven, and wondered where to place a special child... his mother should have this or that quality'... I don't remember the rest as I have purposely tried to forget them. I suppose in the early days of diagnosis, when I was searching for a 'why me' explanation, they afforded some comfort, but later, with a greater acceptance of our situation, I began to loathe them. I feel they perpetuate the myth that parents of disabled children are somehow special... chosen... different from other parents... when, in reality, we are just ordinary families who are coping with extraordinary pressures because we happen to have a disabled child.

I don't believe I was chosen, and, personally, I would hate to think I was; nor do I think I'm special (and even if I was ever under such an illusion, I now have two teenage daughters who regularly remind me I'm not, with alarming conviction). I do know, however, that like all other parents in my situation, I have had to learn an incredible amount, and that our knowledge, experience and skills should be recognised and respected.

So I wanted to write my own article which highlighted this, and, after sitting on an interview panel for the post of manager of a local learning disabilities team, and reading the job specification, I began to wonder what the job description for someone like me would look like. This is what I came up with... (Those of you with sons or daughters with learning disabilities may recognise your role, but for those of you without, when reading, please ask yourself, 'Would I apply?')

	<b>JOB DESCRIPTION</b>
<b><u>REQUIRED:</u></b>	<b><u>MOTHER – FOR DISABLED CHILD</u></b>

**This is a permanent post.**

**Hours:** 168 hours per week, 52 weeks per year

**Time off:** by negotiation with statutory, voluntary or private agencies

**(NOT GUARANTEED)**

**No experience necessary**

**No training will be provided**

**Salary = £0\***

- ❖ Although Carers Allowance is available @ £44.35 per week (*subject to filling in long and complicated forms*)

**JOB PURPOSE:** To provide a full parenting service to a disabled child or children. This includes promoting their human rights, ensuring that all of their needs are fully met and that they take an active part in family life and the wider community.

**ACCOUNTABLE TO:** **Partner, disabled child, other children and extended family**

**ESSENTIAL CRITERIA:**

- The ability to love unconditionally (*under extreme provocation at times*)

- Boundless energy and patience
- The ability to work under immense pressure (*sometimes/frequently with little or no sleep*)
- Must be prepared to work anti-social hours, with no sick leave or time off in lieu
- Physical strength (*This role requires a lot of manual labour; well-developed shoulder and back muscles are therefore essential.*)
- The ability to balance the needs of this child with the needs of other children, and family life (*This could include combining this role with full-/part-time employment and/or study.*)
- A 'thick skin' (*This role receives a lot of criticism; you will need to be prepared to be stared at and judged by others around you at all times.*)
- The ability to negotiate skilfully, advocate and mediate on behalf of your son or daughter (*A good telephone manner would be useful.*)
- Excellent organisational skills (*You will have to juggle a variety of appointments without the support of a secretary/personal assistant.*)
- The ability to multi-task
- Good networking skills, combined with the ability to work independently and use your own initiative
- Must be prepared to become skilled in non-verbal communication techniques and interpretation of body language
- Must not be fazed by body fluids
- Must have an empathetic nature (*be able to work with children/adults who may be distressed*)
- A good sense of humour is essential.

#### DESIRABLE SKILLS:

These skills will be learnt on the job and will be of distinct advantage to you and your child:

- An in-depth understanding of your child's condition, syndrome, impairment; this may include:
  - Epilepsy** (including administration of drugs, including rectal Valium) and/or
  - Genetics** and /or
  - Autistic Spectrum Disorders / 'challenging behaviour'** and /or
  - Physiotherapy, occupational therapy, speech therapy and /or Sign language** (Makaton/BSL) or other communication methods
- Learn to use a variety of equipment, which may include:
  - Hoists**
  - Feeding tubes**
  - Various wheelchairs and adaptations**
  - AFOs (leg braces)**

*You should also be prepared to have countless adaptations to your home, which may include tracking for hoists, ramps, stair gates, locks on doors (which may have to be number locked – a good knowledge of mathematics not necessary, but a good memory vital!)*
- An in-depth knowledge of special educational needs law, procedures and codes of practice
- A knowledge of :
  - The Community Care Act (1990)
  - The Disability Discrimination Act (1995)
  - The Carers and Disabled Children's Act (2000)**
  - The Carers Recognition (and Services) Act (1995)
  - The Carers (equal opportunities) Act (2004)
  - And other relevant legislation
- A good understanding of entitlement under these acts would be an advantage (*see additional notes on legal issues, e.g. complaints procedures, ombudsman, judicial reviews*)
- Experience of working with other agencies – statutory, voluntary and private including Health, Social Services and Education – and attending meetings (*with all of the above, and an*



*appreciation that you will have to repeat yourself, several times to each agency) a distinct advantage.*

- A broad-based knowledge of local politics, i.e. the holders of the purse strings (*speaking at council meetings and writing letters to local newspapers – optional, but occasionally necessary*)

It is possible that when/if your child does leave home, you may be overseeing a Direct Payment and managing an Independent Living Scheme – skills required for this include a knowledge of:

- **Finance** – Direct Payments/ILF/DLA/Clients' Contributions/Housing Benefit and other benefits/tenancy agreements/pensions
- **Accountancy** – time-sheets/wages/BACS/tax/Employers' Contributions
- **Management** – personnel/recruitment/induction/training/supervisions/appraisals
- **Health and safety** – risk assessments
- **Law** – employers' and public liability/employment laws.

This is an extremely demanding and stressful position. You are required to support your child right across the life span. (*It should be stated that retirement is not an option.*) It requires a variety of skills, which you will have to be prepared to learn on the job.

It is recommended that you make contact with others in the same role; these colleagues will be a vital source of support by providing an unconditional ear, understanding, a shoulder to cry on and endless cups of tea (*or occasionally something stronger*) when/if required.

Given the right amount of support, this job can give untold job satisfaction and be extremely rewarding, but, much of this will depend on your ability to negotiate for this support. For this, you will need to be determined, assertive, proactive, accept that you are in a minority, recognise diversity as a good thing, accept that you and your child will be discriminated against throughout your lives, and that, from time to time, you will fail to achieve your goals. Success in this role will see you grow in confidence, ability and knowledge, and become a powerful advocate for your child.

#### **WE ARE AN EQUAL OPPORTUNITIES EMPLOYER.**

**Failure to meet any of the above criteria will not affect your being considered for this position.**

**PLEASE NOTE: The Parental Leave Directive does not apply to this post, and the right to apply for flexible working arrangements is waived.**

**Gail Hanrahan © 2005**

The editor of the next PMLD LINK is

### **Rob Ashdown**

**The copy date for all articles, information and news for the winter issue is the 1st October 2005 and the focus is on 'Meaningful Involvement'.**

Articles can be long or short and they are welcomed from carers or professionals alike – we value YOUR experience and views. Please contact us if we can help you in any way. If you have any picture or photos to include we would love to see them (providing we have permissions).

Please send contributions to: Rob Ashdown, St Lukes School, Grange Lane North, Scunthorpe, N. Lincs DN16 1BN  
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## First Impressions

### Emotional and Practical Support for Families

By Marie Broad, Support Officer, and Jill Davies, Research Programme Manager, Foundation for People with Learning Disabilities

The health, education and social sectors are increasingly recognising the importance of early childhood intervention for children with learning disabilities. New initiatives, such as the Department for Education and Skills' (DfES) *Together from the Start* (2003) and the *National Service Framework for Children, Young People and Maternity Services* (Department of Health (DoH)/DfES, 2004) highlight the benefits of the Key Worker model and single assessment procedure.

The picture may at first appear rosy, but the emotional well-being of parents raising a child with a learning disability continues to be neglected. New research from the Foundation for People with Learning Disabilities (FPLD) reveals that many parents raising a child with a learning disability do not get the support they need. This research led to the publication of *First Impressions: Emotional and practical support for families* – a booklet for families of children with disabilities from the time of their child's diagnosis – and a report for practitioners and policy-makers.

Interviews were carried out with 22 parents, three of whom had a child with profound and multiple learning disabilities. The research study found that, for some parents interviewed, the disclosure of their child's disability was handled sensitively, but, for around half of the parents, the experience of diagnosis was less positive. One mother of a five-day-old baby was told: 'There's no beating around the bush; he's got Down's Syndrome.'

Support was found to be patchy and difficult to access. Provision and quality of support depended upon where families lived and the attitude of their health practitioner. Some parents were given information, but others received very little, and resorted to searching the Internet for help. It was found that: parents weren't able to spend quality time with their other children; they encountered housing and financial problems; and raising a child with a learning disability put strain upon relationships with partners.

Many day-to-day activities proved to be difficult for parents, such as finding an appropriate shopping trolley, parking without a disabled parking badge, using public transport, and finding a strong enough buggy as the child grew older.

For parents of a child with profound and multiple learning disabilities, life can be even more of a struggle. To start with, there are multiple appointments to attend with a barrage of different professionals. This can take up a lot of time in travelling and waiting to be seen. It also takes



effort to meet and get to know a large number of professionals, and energy to explain the situation to each new person involved.

Adaptations often need to be carried out on the family home to provide full support for the child. These can often reduce living space, and, with all the medical equipment, can make the house look almost like a hospital. Adding certain adaptations, such as a lift or an adapted bath-

room, can have a large impact on selling the property if the family decide to move house at a later stage.

The level of care provided by the family can take its toll on their emotional well-being. For example, interrupted sleep and the time needed for tasks such as feeding, toileting, administering home oxygen therapy and making sure the child is in a comfortable position can add to emotional and physical stress. A study by McLean et al. (2000) confirms the extra burden of caring for a child whose life is constantly threatened. They compared families of premature infants who were on home oxygen therapy with 10 families of premature infants who were not, and found that those using oxygen therapy felt the care required had a significant effect on the family. Mothers reported significantly less vitality and more mental health problems.

In another study, Redmond and Richardson (2003) explored the needs of mothers caring for young children with severe to profound and life-threatening disabilities. Results showed that a large majority were experiencing increased levels of strain and encountered higher levels of unhappiness and depression.

Most parents have other children to care for too, and juggling the needs of all the children can be a challenge. With little time left for themselves, parents can find that employment possibilities are very limited and not sustainable. Where one parent takes on most of the caring, they may be left feeling very isolated, while the parent who is working can feel left out in terms of what is going on with their child because most appointments are made during their working hours.

One family's story is told here. The mother was interviewed as part of the research study and highlights some of the day-to-day difficulties facing these families. (Names have been changed.)

*Zara and Chris live with their three children in London. Daughter Lisa has Rett syndrome. It was during a routine check-up, when professionals started to act differently towards Lisa, that her parents realised something might be wrong. Lisa was not weight-bearing, and referrals for blood tests kept being made, but no full explanation was given as to why tests were being carried out.*

***They made us feel we were pestering***

***them every time we asked a question.***

*A year later, more tests were carried out, including some brain scans. As before, the paediatrician kept them in the dark about what was going on. Finally, he announced that it was likely that Lisa had Rett syndrome, and gave them a leaflet about it, but did not offer a follow-up appointment or immediate support from a health advisor. After this, the family were seen by a specialist in Rett syndrome who confirmed that Lisa had the disorder.*

*Chris and Zara were thankful that at least that they now had a diagnosis. They got in contact with the Rett Syndrome Association, and attended some weekend seminars. This allowed them to meet other parents with children the same age as Lisa. At the seminars, they were also able to find out about financial support available, such as Disability Living Allowance.*

*Life has been tough on the family, both physically and financially, especially with the time required to care for Lisa's additional needs and the extra support costs. The family were living in an area that did not offer home-based services such as Portage, a special needs health visitor or a Key Worker system, so Chris and Zara found they had to rely on each other for support.*

***You have to do it yourself – you get tougher as the years go on.***

*As the family couldn't get funding to pay for 1:1 support at a local mainstream nursery school, they had to find and pay for a helper themselves. Zara had to take Lisa's specially adapted chair into nursery every day because they didn't have the right equipment. Eventually, Lisa was given a place at a special school, and, before she started there, a teacher visited her at home. This was really helpful and encouraging for the family.*

*When the family moved house, they also had to change to a different GP. Finding a new surgery was a challenge, as there seemed to be discrimination around taking Lisa on due to the number of referrals needing to be made to a range of therapists.*

*Zara has taken on the main caring role, and this means having little time to pursue interests or even meet up with friends. She*

would love to go back to work, but cannot find a job that would fit in with caring for Lisa. Old friends have distanced themselves from the couple, as they feel awkward and don't know what to say.

**Friends walk away from me in the playground...it's like being invisible.**

Zara often feels isolated and alone, and her only real support is Chris. Other members of the family have also grown further apart from them. Chris's parents do not like to get too involved, as they find it hard to understand Lisa's disability.

Lisa's brother and sister like spending time with her, but sometimes they get frustrated with family outings because they have to be tailored to Lisa's needs; this often means the family being divided so that they get a chance to do things they can't do if Lisa is with them, although they are happy when they get to jump queues at the theme park when Lisa is around!

But the good news is that Lisa has some great friends whom she likes to bring home from school. Her friends want to help her with feeding and other support, and really make a difference to her enjoyment of life. The school offer a stable support to Lisa and her family, and have kept Zara going when carrying on has been hard.

**The future**

The study discovered that the range of support offered to families with children with profound and multiple learning disabilities is patchy throughout the UK. However, things are changing for the better. The National Standards Frame-

works for Children in England and Wales highlight the importance of single assessment procedures and Key Workers for parents of children with very complex needs, which will alleviate some of the additional stresses for parents described earlier.

The voices of families from the study have shaped the contents of the *First Impressions* booklet and report, and they have been written with a view to highlighting what families have told us was helpful for them. The booklet for families offers practical advice on topics such as coping with initial diagnosis, pre-school education, getting help, family support and financial advice.



To get your free copy of the booklet, *First Impressions*, please call the FPLD's Customer Services on: 020 7803 1101 or email [fpld@fpld.org.uk](mailto:fpld@fpld.org.uk). The report for practitioners and service commissioners, based on the same findings, can be downloaded from [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)

\*All photos were taken at a Family Fun day, March 2005.

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## Supporting Parent Power A Somali Disability and Elderly Support Group – a personal account

By Sarah Chandler

Regional Development Officer (West Midlands), Contact a Family

*Contact a Family is a UK charity which supports families of disabled children aged 0-19 years. There are offices in London, Scotland, Northern Ireland, Wales, the North-East and North-West of England, and the West Midlands, as well as seven projects in London Boroughs. We provide medical information through our Directory of Rare Disorders and Specific Conditions and links to parent groups, information about services and support available, fact sheets and guides on numerous topics, workshops for families and professionals, newsletters, an award winning website, a linking service for families, events, research and much more.*

I joined Contact a Family over two years ago as the Regional Development Officer. The first real piece of work I had to undertake was a piece of research for the Birmingham Children's Fund called 'We're Listening'. It was through this research that I found myself working with the Somali Disability and Elderly Support Group.

I was contacted by a Health Visitor who said that the group were in the early stages of setting up and needed some guidance and support. Being a white, middle-class woman, I wasn't sure if I was the right person to help the group, but thought that the very least I could do was meet them and see what they needed. I had concerns about whether I would be able to communicate effectively with the group, whether it would be better to find a Black African organisation to support them, and whether I should work with a group looking at the needs of such a wide age range.

After puzzling around these concerns for a few minutes, I pushed them to one side and thought, 'Well, I'll never find out if I don't ask' – so I did. I initially met with three members of the group – Ahmed, Essa and Mohammed. Two of the group have children with autistic spectrum disorders. The issues for families with disabled children and adults among the Somali community in their area were as follows:

- Lack of understanding of the health and care system
- Lack of awareness of their rights to assessments, services and benefits
- Many Somali families speak little or no English or are not confident to speak English with authorities
- Lack of care workers who speak Somali or

understand the culture

- A high rate of unemployment.

There were a number of issues for the group, including finding an office base and creating a more effective structure. Members of the management committee had attended some training events, but needed more one-to-one support to write funding applications, set up training for volunteers, and set up office and finance systems. They also had a vision of setting up a centre for family activities – grand plans for such a small group, but nothing had quite prepared me for their ambition, drive and enthusiasm for getting things done in their community.

Initially, I met with the group at one of the member's homes and we spent some time listing the issues and turning them into a short-term action plan and a list of longer-term actions. The short-term action plan included:

- Training for volunteers
- Funding for an office base
- Leisure opportunities for children
- Family-friendly workshops on educational issues
- Finalising the group's constitution
- Applying for charitable status
- Developing a service to provide Somali-speaking care workers to give respite and home care services
- Training for committee members.

I then met up with the group as a whole every two months to review progress, and, in between times, I met with one or two key members to focus on specific pieces of work. I would go through funding applications with Ahmed and

Fatima, and, later, with Ali, a new member who became the co-ordinator. We were successful in a number of small applications – the Local Network Fund and the Millennium Awards Scheme. This helped the group to run training for volunteers, workshops for families, open a small office in Small Heath, Birmingham, and pay volunteers' expenses. They also had some money to pay for insurance and buy some equipment for children to use.

To begin setting up the training for volunteers, we first agreed the current needs of the volunteers, and then looked at other organisations who could provide training to the group. We set up a 10-week programme to cover topics such as benefits, working with carers, respite services, etc. The group were initially reluctant to make calls to other organisations themselves to book speakers and training sessions, so, in the beginning, I would make calls. After a very short time, they made calls themselves and booked additional training. The contact with other organisations was a good networking experience for the group as a whole, as they now have a larger base of colleagues to call for information and advice.

I also spent some time with Mohammed and Ahmed following up on the need for Somali-speaking care workers. We met with Crossroads to discuss the issue, and Mohammed and Ahmed followed this up so effectively that the project is now in the process of recruiting and training Somali people to become care workers for Crossroads.

### **Networking with other workers and organisations**

To develop leisure opportunities for disabled children and other children in the local community, I put the group in touch with Laura Watts, a very skilled development worker who works part-time for the Early Years Partnership and part-time for a voluntary organisation called Dens of Equality. Dens of Equality works with small groups of parents around the city to set up inclusive play and leisure in their local area. Dens has successfully set up and supported over 10 groups in the city.

Laura supported the setting up of a new group called SKIN (Somali Kids Inclusion Network) that aims to develop inclusive play in Small Heath. The group subsequently held a fun day for parents and children before Christmas to give children a chance to try a range of new activities, including games, arts and crafts, badge-making,

story-telling and dancing. For the women who came along, it was the first time they had met together. Needless to say, everyone enjoyed the day, and, for SKIN members, it was a confidence-booster that inspired them to put on more events.

### **2005**

The group has gone from strength to strength. They have now moved to a much larger base, and support a range of other groups from the area including two football clubs, a group looking at mental health issues, a business consortium, a community internet radio station and a women's group. They hope to develop their base into a local community centre. They have funding from Social Services for three years to pay for rent and a part-time co-ordinator, and have applied for funding from various other sources.

I continue to be involved with the group, albeit on a less intensive basis – usually meeting up with them once a month and then giving information via email or phone. I would love to take the credit for what they have achieved, but I have given only information, contacts and time that I am paid for. They have committed their own money, free time and energy, and followed their vision. They have worked hard to achieve all that they have done, and I am in awe of their achievements. I have learned a lot from being involved with them, and feel that I am privileged to have had the opportunity.

There are many other groups of parents around the region and country who are getting together to set up services and support for families. They have evolved to fill the gaps that statutory services fail to meet. Without them the stresses on statutory services would be far greater – we all need to do much more to help these groups develop and grow.

Finally, I would like to add a big word of thanks to all those parents who take the time and use their energies to improve services for everyone – it is appreciated.

*To find out more about the work of Contact a Family West Midlands, telephone 0121 415 4624. Families can contact the freephone helpline on 0800 808 3555.*

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## **Team Around The Child (TAC) Helping to Keep Families Strong**

By Peter Limbrick

There are two assumptions implicit in this title. The first is that families are strong before the arrival of a child with profound and multiple learning difficulties. Logically, this must be no more or less true for this minority of families than for families in general. The second assumption is that having a baby or young child with profound and multiple learning difficulties might pose a threat to a family's strength. The title also asserts that the Team-Around-the-Child (TAC) approach, when used as the core of an early intervention strategy, can help counter some of the common threats. This article will explore how the strength of a family might be jeopardised, and the potential for TAC, as a collective effort, to help.

In addressing the second assumption, I must avoid the danger of describing the arrival of the new family member in wholly negative and tragic terms. This would be a disservice to people with disabilities and special needs, who are no more tragic than the rest of the population. Of course, some babies are born with conditions which leave them with continuing serious illness, and some will have short or uncertain life expectancy. This fits within most people's definition of a tragedy within a family whether or not the child also has a disability and special needs.

So what is it about the arrival of a child with profound and multiple learning difficulties that might threaten a family's strength in the first months and years? In my experience, the threats can be grouped under the following headings.

### **Changes in relationships within the family and beyond**

If two parents are living together, their relationship is likely to change. For some couples, the relationship can be strengthened. For others, it might deteriorate quite quickly. If it deteriorates significantly, one parent might leave. The relationship can falter because of differences of view about the cause or seriousness of the condition or about the validity of the diagnosis (if there is one). There might be differing attitudes to disability, and differing willingness or ability to alter long-held views. A partner can be overwhelmed and disempowered by such negative emotions as guilt or anxiety about the child's well-being and future prospects. A partner might have ideas

and aspirations which cannot embrace a child with profound needs.

Other relationships in the family can be affected too. Siblings might feel things are not the same any more, and see their parent or parents as less available, less tolerant, less loving. While this impacts on the children themselves, it is also likely to be a further reason for parental guilt. Relationships with parents' parents, in-laws, brothers and sisters can all be tested. Friends and neighbours might turn away because of their own attitudes to disability and because they are afraid they will not know what to say or how to help.

### **Stresses and strains in looking after the child**

A family can be subjected to continuing stress when a child is unable to eat or drink enough, is subject to persistent and unexplained crying at all hours, is repeatedly ill or fails to thrive. Some infants are subject to all of these. Stress and anxiety might be increased when the child's health and well-being depend directly on a complicated regime of medications and nursing procedures carried out by a parent at home. Not only does the parent have to know what to do, they have to observe the child skilfully to know when an intervention is required. If they get it wrong there will be consequences. Other causes of stress in the family home can be lack of sleep for everyone, and few or no opportunities for family members to get a break from these tensions and from each other.

### **The practicalities of running a home and a family**

Each family grows and thrives within a set of practical conditions, including finance, accommodation, work, transport and leisure. Each of these can be at risk of a more or less severe downturn in the first months and years of bringing a child with profound and multiple learning difficulties into the family. Expenses are likely to increase significantly; the family home might no longer fit everyone's needs; paid work might become less manageable (and the income from it reduced or lost). There will probably be many more occasions than usual when children and equipment need to be transported to clinics, consultations and centres beyond the neighbourhood (with perhaps reduced access to private transport); there are likely to be reduced opportunities for evening and weekend leisure time; and, lastly, holidays away from home might become very difficult or impossible.

### **Ineffective support for the child from local services**

Ineffective support for the disabled child can add to the family's anxiety and stress, impede their adjustment to the new situation, and spoil their coping strategies. The major reasons that support from the statutory services can be ineffective include:

- The absence of relevant support (still the experience of many families in the first months)
- Parents feeling they are not allowed to be involved in decisions about their child
- Inflexible provision which is offered on a 'take it or leave it' basis with no reference to actual needs
- Fragmented support in which appointments and home visits are chaotic, disruptive and unmanageable
- Delivery of development and learning programmes to the child on a piecemeal and disjointed basis.

If we are prepared to credit families of children with profound and multiple learning difficulties with being initially just as strong as other families, then perhaps we can also have faith that the majority of families, if given timely and relevant support, will, after a period of uncertainty, confusion and floundering, regain a more even keel and a sense of purpose and

direction. The child with profound and multiple learning difficulties will gradually stop being so 'special' and will assume their place in the family from which they benefit and to which they contribute. This positive outcome must be a major aim of family-centred early support services.

How can the TAC approach help keep families strong? TAC is not a brand name nor should it be thought of as another fixed system into which children and families must be persuaded to fit. The principle behind TAC is merely that when a few practitioners are working closely with a child who has profound and multiple learning difficulties, they should agree to collaborate closely with each other and with the parent or parents. This joined-up approach appeals to most parents as just common sense. So what can TAC, as a collective approach, do to help keep families strong and to counter those threats which are frequently consequent on the arrival in a family of a child with multiple and complex disabilities?

The TAC is defined as an evolving and individualised collaborative team of the *few* practitioners who see the child and family on a regular basis to provide practical support in education, therapy and treatment. It offers a full place to parents (and other family members if the parents wish), and it ignores all agency boundaries. Its contribution to effective support is as follows:

1. Each TAC comprises just a handful of people whom the family know well and trust. Members join and leave as needs change. As only one or two people change at a time, the family benefits from a continuing support system which remains seamless even over major transitions.
2. Parents have the reassurance of seeing their key practitioners meeting together, every half-term or so, to share observations, iron out contradictions and learn what each other is doing. This collaborative effort allows parents to contribute to and share in an agreed and balanced collective view of the strengths and needs of the whole child and the family.
3. Parents, as full members of their TAC, are informed, involved and empowered in all aspects of the child and family's support.



This is *genuine* partnership with a straightforward process and a visible, practical outcome.

4. TAC sits with the child and family at the centre of their support network providing joined-upness at what ever level it is currently required. Penny Lacey (Lacey, 2001) argues that liaison, co-ordination and collaboration 'can be conceived on a continuum, with liaison indicating the least degree of communication between agencies or professionals through to collaboration indicating the most'. Each TAC, as a collective effort for a child and family with multiple needs, will liaise as necessary with other services (for example, housing, benefits and transport), will ensure that such interventions as clinics, assessments and home visits are co-ordinated in space and time as far as is possible, and can facilitate close collaboration on the child's development and learning programmes. For those practitioners and parents who are willing, the TAC is a forum for a full transdisciplinary approach with unified assessments and fully integrated education/therapy programmes.

Walsall Child Development Centre has recently asked parents how the TAC approach has helped their families. The main response was that by having TAC, there was more focused and effective communication. Parents found that they did not have to do everything for themselves, but that when a problem arose they contacted their Key Worker, and the TAC responded as a whole. Parents found that things happened more quickly and appropriately so that they did not have to expend time and energy on chasing appointments and actions. Parents valued that any family member could attend reviews – which is very different to the conventional 'medical' appointment system which expects only parents to attend. By actively involving extended family members in this way, parents felt their support network had been extended. Walsall CDC gives an example of how TAC can help keep the family strong:  
Child X is eight months old and has complex physical needs. His mother, a single parent, has an older daughter of four. Her concerns initially were not only related to child X, but also focused around the impact of her son's

disability on her daughter, whom, she felt, was being left out and not being given the time and attention she needed. Her main concern, as documented in the Family Service Plan, was to have some free time to spend with her daughter and also for herself. Her TAC, which include this family had concerns regarding the acceptance and understanding of their child's condition by the paternal grandparents. Also, initially, the father found it very difficult to come to terms with his son's disabilities. The TAC was therefore set up with an objective that father could be fully involved in all aspects. To this end, reviews were held to fit in with father's work shifts. Appointments at home by the physiotherapist and early years worker were also booked for when father could be present in order that he could fully participate in programmes of intervention. These programmes were video taped so that other family members could be involved in the child's care. This led, at the parents' request, to involving the grandparents in appointments and reviews, and to supporting them in delivering the child's Physical Management Programmes. These parents value their TAC for facilitating more open dialogue between the various members of the family.

There is no average UK family. There is wide and welcome variation in composition, circumstances, culture and beliefs. Responses to a child with profound and multiple learning difficulties will vary as will the strengths of family members. Different families have different needs, and these will change with time within each family. Effective early intervention for a family whose child has profound and multiple learning difficulties must be a collective effort which empowers parents, helps keep the family strong and responds flexibly to the needs of each individual child and family. TAC provides a forum for this collaborative family-centred approach.

*I would like to thank Walsall CDC for their help in writing this article.*

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## Team Around The Child – the Key Working Approach

TAC practice in Wolverhampton

By Jill Wellings, Head of Special Needs Early Years Service and  
Wolverhampton ESP Co-ordinator

In 2002, Wolverhampton Local Education Authority and Primary Care Trust established a Key Worker Pilot Project, based on the Team Around The Child (TAC), for families who have a pre-school child with complex needs. This article discusses the background and evaluation of the project, then looks at how the project has moved forward since the LEA/PCT became an Early Support Pathfinder in 2004.

### **Background**

For Wolverhampton, the question was not one of 'Should we introduce Key Working?', but 'How...?' At the time, we talked to both parent groups and individual parents of young children with disabilities in the area who felt happy with the majority of services. They appreciated that some professionals tried to do joint home visits, but they felt services could be better co-ordinated. If four or five professionals visiting the family were presenting different individual programmes for a child... 'Why can't they be combined?' asked one parent.

Parents were not asking us for a new service – they wanted the specialist individual support; all they were asking was that existing services should be co-ordinated. This seemed a logical, simple request.

The TAC approach (discussed in the previous article by Peter Limbrick) seemed the ideal model. It was about us putting our services around the family, not fitting the family into our service.

### **2002: Beginning the process**

With only a small amount of money available to commission our independent consultant, Peter Limbrick, to carry out an evaluation after the TAC approach to family support had been implemented, we started our Pilot Project with eight families.

### **Selecting families for TAC**

Professionals working with families whom they thought would be suitable for TAC made referrals to our Multi-Agency Referral Panel. The eligibility criteria applied were that the family referred should have:

- a child with complex needs between 0 and 3 years

- three or more professionals involved with the child on a regular basis
- given their permission for a TAC to be implemented after a discussion with a consultant paediatrician, during which they stated their with first and second choice of Key Worker.

The initial selection of families took into account the range of family need within the area: families of children with a variety of complex needs; families from ethnic backgrounds; and families who had service access difficulties (e.g. asylum seekers).

### **2003: Evaluation of TACs**

The aim of the evaluation was to determine whether the delivery of services for children with complex needs in the Wolverhampton area was improved by providing the family with a Key Worker. To establish whether this was the case, Peter Limbrick, our independent consultant, carried out structured, confidential interviews with all of the eight families and sent out a questionnaire to survey the views of TAC members.

### **Families' feedback**

#### *Focus 1: The TAC team*

Of the eight families, four of them had been given their first choice of Key Worker. They all valued having a Key Worker to co-ordinate services. They enjoyed the collaboration with professionals and felt that their views were taken seriously.

Parents' comments:

*I've got a great team to help me. I like the meetings and look forward to them.*

*I am thrilled by the Key Worker Project. It would have been valuable earlier. In the first year, we had numerous professionals,*

**Table 1: Timetable of implementation for Wolverhampton TACs**

Date	Stages of implementation	Details
September 2002	Professional training	Senior line managers' training.
	Selection of TAC families	Consultant paediatricians contact families, asng for first and second choice of Key Worker.
October 2002	Professional training	Key Workers' and TAC members' training.
November 2002	Implementing TACs	Key Workers talk to families to establish TAC.
December 2002	TAC meetings	Key Workers call initial TAC meetings. Family Service Plans formulated. Regular meetings held following this.
June 2003	Evaluation	Independent consultant interviews individual families, and surveys line managers/Key Workers/TAC team members via questionnaires
July 2003	Celebration day	

*a fragmented service and conflicting advice. The first [TAC] meeting was so useful; we ironed out different approaches and agreed clear, consistent objectives.*

#### *Focus 2: TAC meetings*

The frequency of the TAC meetings was agreed individually, but meetings were usually timed to last 60–90 minutes.

Parents' comments:

*We have a meeting every three months at home. All the children are here. My Key Worker is really good at leading the meetings.*

*The time is just right, 60–90 minutes. I don't do tea.*

*Doctors try to take control. TAC does not.*

*The meetings are informal. They are important because we discuss activities and agree next goals.*

#### *Focus 3: The Family Service Plan and integrated goals*

Parents' comments:

*Yes, I got a report. My reading isn't very good but I understand it.*

*It is useful because I can refer back to it. I understand it. Everyone is sticking to the plan.*

#### **Professionals' feedback**

From the evaluation of the questionnaires given to professionals, there was a general consensus that they enjoyed working closely together as a team. Some of the professionals had previously felt isolated and thought this way of working supported the TAC goals of service integration and sharing of skills.

Professionals' valued:

*The opportunity to thoroughly discuss why I am doing something and to develop that thinking and planning alongside another professional.*

*[That] a structure is provided for liaison with other agencies in which the parent is more in control.*

*Having more information about what was going on and empowering the family to make choices and be involved in decision-making.*

*[That] a Key Worker co-ordinates the TAC group and feeds to outer circle. A Key Worker is the link person for the family to any queries they have. A Key Worker should attempt to ensure that all services the child/family require are explored.*

*[That] I'm more confident. I am not giving conflicting advice.*

**Summary**

The pilot project had succeeded! Major elements of this success were the enthusiasm of both the parents and their professionals, and the willingness of all to invest their time and energy in a new approach. Due to a relatively small specialist workforce in this area, and their commitment to the approach, the model of working started to roll out spontaneously for other families.

However, alongside the success of the pilot, we recognised a number of issues that would need to be addressed for the project to continue and develop. These were:

- The choice of Key Worker
- Administrative support for the Key Worker
- The needs of the child/siblings during TAC meetings
- Interpreters
- Training.

**Ways forward*****The choice of Key Worker***

The success of the Key Worker role depends upon developing a relationship based on trust and honesty with the family. Hopefully, giving the family some choice over who their Key Worker is to be embeds this philosophy.

The Key Workers themselves act in a co-ordination role for the family, keeping a record of all agencies involved with them and agreeing with the family who is to be part of their TAC. The size and make-up of the team varies from family to family. The Key Worker discuss the venue for the TAC meetings with the family and, again, this will vary from meetings in the home to meetings at a specific venue. Among current teams, some are as small as three professionals with the family; others have up to eight members; some of the teams include grandparents and child minders.

We recognised, prior to becoming an Early Support Pathfinder, that some services had a higher involvement than others with children with complex needs, so their staff were more likely to be selected as Key Workers. These services would require additional support if we were to deliver high quality input into Key Working. Therefore, the Early Years Development and Child Care Partnership, through its special needs funding, has supported the appointment of development workers to speech and language, physiotherapy, sensory inclusion and early years services.

***Administrative support for the Key Worker***

The Key Worker role carries with it a significant administrative burden. The Key Worker is responsible for managing the meetings, co-ordinating the Family Service Plan, and, recently, introducing the

Early Support Family Pack. In 2002, no administrative support was provided for Key Workers, and this did create considerable work for those involved. However, all Key Workers now have administrative support for their meetings, which has eased one of the major difficulties highlighted in the Pilot. Early Support Programme funding has enabled the appointment of a manager/administrator to support individual Key Workers in their planning and administration.

***The needs of the child/siblings during TAC meetings***

As well as the manager's appointment, the Early Support Programme has funded the appointment of two development workers who can support the child and any siblings during the TAC meetings. During the pilot project, we were very aware of this need, and felt that, for parents to be fully involved in the process, they needed the reassurance that their children were being fully supported during meetings.

***Interpreters for families***

The ongoing commitment to having regular support from interpreters was considered to be essential, with funding set aside to maintain continuity when required. For TACs to operate successfully, consistent access to an individual interpreter is required so that they come to understand the situation. This was highlighted as a difficulty for one family during the pilot.

***Training of Key Workers***

Training and a programme of support for Key Workers is pivotal to the success of the TAC. After initial training, regular meetings are held to support Key Workers, and a rolling programme of training, which includes courses on counselling skills, benefits and housing issues, is in place.

**Conclusion**

Although we are a long way from the infancy of the Key Worker Pilot Project in 2002, we still feel we are in the early stages of our journey towards providing a seamless service for all families who have children with complex needs. However, in commencing that journey, and listening and learning as we move along, we hope to re-shape our services so that we provide a fully integrated TAC for the families who need it. With the development of Early Support, we have a real chance of delivering and sustaining quality services for families. In the words of one of our Key Workers: 'It's the way of the future.'

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## Planning for Transition

### The Importance of Parents' Expectations

By Fran Russell

#### Introduction

*'Why me?' is one of the first questions we ask ourselves when we learn our child is, in some way, fundamentally different from other children... Soon we alternate this question with, 'Why my child?' ... For me, the final answers to these questions were not as important as the searching for the answers. I thought that the answers would make the pain go away. As I look back, I realise it was the searching which healed. By virtue of seeking for an answer, I realised that I had something to learn. ('Holly', in Clarke et al., 1989, p. 19)*

When a couple plans to have a family, or finds out they are having a baby, they will develop hopes, dreams and expectations of the future for themselves and their child. When they learn that their child is disabled, their hopes and dreams can quickly fade, and their expectations can be shattered as they begin to face an uncertain future.

I have talked with many parents of disabled children who, like Holly, go on to learn from their experiences and develop their knowledge and understanding of their child's abilities, as well their disabilities. They find out about what support and opportunities are available to them and their families, and the means to access them. As a result, parents with a disabled child begin to develop new expectations of their future as they adjust to their new situation. As Holly suggests, this process is as important as the answers to the questions for these parents.

This process of developing expectations is repeated for parents/carers of disabled children during every transition in their child's life when they are likely to encounter different services, support and procedures. My son, Paul, who has a learning disability, is finishing college this summer, and we are currently considering leisure, work and housing opportunities available to him as he moves into adulthood. Our family, including Paul, are extending our experiences, knowledge and understanding of options that are available and developing expectations concerning what might be possible. We went through similar processes when Paul started nursery and school, transferred to high school and then on to college. On reflection, our satisfaction or

dissatisfaction with the services and support we received was related to our expectations of the outcomes.

My experiences with Paul prompted me to explore parents'/carers' expectations during their first experience of transition – starting school. This paper provides a brief summary of this research and a description of work I did as a result with one family as their child started school.

#### Parents' expectations

Expectations are personal beliefs about what will happen in the future and are based on an individual's beliefs, personal experience and the information they receive from a variety of formal and informal sources. Expectations are influenced by interaction with individuals, organisations, legislation and cultural values. Unrealistic expectations can result in disappointment and difficult relationships between families and professionals, so supporting families to develop expectations that are likely to be realised can lead to more positive outcomes for all concerned.

The parents/carers involved in my research study developed expectations of their child, the support they would receive in school and local SEN systems and procedures. Overall the most important expectations of this group were that their child would make progress at school and that the staff involved would be committed and have expertise or access to training.

The parents'/carers' expectations were developed over time as they gained greater experience and gathered more information.

**Table 1: Positive and negative outcomes of expectations**

EXPECTATIONS				OUTCOMES	
<b>Positive expectation</b> Thomas to have access to specialist programmes at a special school	→	Realised	=	<b>Positive outcome</b> Thomas attends special school and has access to specialist programmes.	
<b>Negative expectation</b> Lee to find it difficult to settle in school	→	Not realised	=	<b>Positive outcome</b> Lee's learning support assistant works sensitively with Lee and he settles into school well.	
<b>Positive expectation</b> James's mother expected to be involved in meetings to discuss James's individual programme so she could continue it at home.	→	Not realised	=	<b>Negative outcome</b> Meetings took place in school to plan James's individual programme but his mother said she had not been involved.	
<b>Negative expectation</b> Yvonne's mother had concerns about the attitudes of the staff in the school.	→	Realised	=	<b>Negative outcome</b> After two terms of Yvonne being in school, she was still attending part-time only because the staff said she became tired.	

They reflected the individuality of the families involved and stories they told as they were based on parents'/carers' own beliefs about disability and education, their experiences with their child, support services and schools and their understanding of information they were given during the transition process.

The content of a person's expectations can be positive or negative (see Table 1). Positive expectations are those that are concerned with what a person would like to happen; for example, the parents/carers in this study wanted and expected their child to make progress at school. Negative expectations develop when the parent/carer envisages that something may not go well; for example, that their child would find it difficult using school transport.

Expectations can also have positive or negative outcomes (see Table 1). Positive outcomes occur when a positive expectation is realised or when an anticipated difficulty being avoided. Conversely, a negative outcome happens when a positive expectation is not realised, and can also occur when an anticipated difficulty becomes a reality.

Positive outcomes can pass unnoticed, but will enhance parents'/carers' confidence and feelings of well-being, whereas a person's attention is drawn to negative outcomes which can result in confusion, anger directed at the people they believe are at fault, and low self-esteem. This can have a detrimental effect on the relationships that develop between home and school.

When parents/carers were asked to review their expectations after their child had been in school for a year, most of them had either been realised or developed further since their child had started school. Those expectations that had not been realised were mainly concerned with parents'/carers' relationships with school and the organisation of support within school.

### **The importance of parents'/carers' expectations**

If schools want to encourage parents/carers to play an active role in their child's education, professionals and practitioners need to support them to develop expectations that are likely to have positive outcomes.

During the analysis process for this study, the Parent Advisory Group noticed that the parents/carers involved often based their expectations on limited experience and an inaccurate or incomplete understanding of the information they had been given and the processes they were involved in. Parents/carers need ongoing and accurate written and verbal information to develop an understanding on which to base their expectations. Opportunities for parents/carers to broaden their experiences by visiting potential schools, talking to a variety of professionals and practitioners, and asking questions can help them to develop their thoughts, ideas and expectations. For example, the areas where expectations are less likely to be realised are those, in my experience, where parents have limited experience, are rarely discussed as part of the statutory assessment process and are not included in the child's written statement, if they have one. Parents/carers therefore have no clear basis for the expectations they develop.

Talking with the parents/carers as part of this research raised their awareness of their expectations. Yvonne's mother said that, because of the interviews, she began to realise what she was expecting of the future, which helped her make decisions about Yvonne's education, and Lee's grandmother took her list of expectations compiled through the study into school to discuss them with the members of staff who would be caring for Lee. They had all been realised by the end of this study.

### **Transition planning**

As a result of this research I began to consider the process of transition into school from parents'/carers' perspectives, and how they could be supported to develop expectations that are likely to have positive outcomes. In my experience of working in pre-school support services and supporting families through their child's transition into school, I have found that, for many families, the focus during this process is on the child, and little consideration is afforded the parent/carer other than to consult with them and keep them informed. Through my work with one family, I was able to alter the focus of the support offered to help the family to develop their expectations about their child starting school.

I had been Ben's Portage home visitor for over a year when we began to discuss his future education. He has Down Syndrome and his family also attended a family support centre where they met with other parents of disabled children. Around Ben's 2<sup>nd</sup> birthday the family visited schools and discussed their options with professionals involved and parents they met at the support centre. They chose a local mainstream nursery for Ben. Before he was due to start, we contacted the services who would support Ben in school. During the term prior to him starting, we arranged meetings with the school, and Ben and his mother joined in several nursery sessions. This enabled Ben's mother to meet the staff and children, gather information and gain experience of the nursery routine and how Ben responded. During the Portage visits, we discussed the information Ben's mother had been given and her experience of nursery so she was able to develop her ideas and expectations before he started.

### **Outcome for the family**

On reflection, Ben's mother said that, although she wanted Ben to go to a mainstream nursery, she remembered having negative expectations. She had expected him to be bombarded with support and so not have the freedom to mix with other children and make his own choices about where to play. She feared that Ben would cry and become clingy so she would need to spend some weeks with him in nursery to help him settle. She had expected the change of environment to have a detrimental effect on his behaviour and communication. During the transition process, these expectations developed and became more positive. For example, she knew that support had been organised and was in place ready for Ben to start. She understood how the support assistant would work with Ben to provide help when he needed it, and how information would be shared with her at the end of each day. Through the visits to nursery, she also became familiar with what happened in nursery, and saw how Ben and the other children would play together.

After Ben had been in nursery for 6 months, she said that the outcomes of all her expectations had been positive, and Ben's

transition into nursery had gone well. She said that this had been helped by the support she had received through Portage and the family support centre, talking to professionals she met and other parents, visiting different settings, and knowing that the school had previously had experience with another child with Down Syndrome. When asked to comment on the transition work we had done together, she said:

*I think the visits to school were great because if a school knows you're coming in to visit and look around their nursery, everything will be just so. Whereas if you go in on a couple of visits, you see the good and the bad points of a situation. You get to see the children. You get to see some form of structure.*

She also said that a Personal Passport she had made had been helpful. Based on an idea presented at the 2003 National Portage Conference by a parent, Clare Cosser, it provided written information through Ben telling his own story and saying what he liked and disliked, what he could do, when he needed help and what his family wanted him to achieve.

*The Personal Passport was invaluable really because it says everything Ben would say if he could, and information that I wish to get across, but I could not be there telling them every day – things that they might forget.*

Ben took this into nursery so the staff could refer to it when they needed.

### **Outcome for the school**

During a follow-up visit, I talked to the nursery teacher who said that she had found this approach to transition useful. Usually, the

school had a meeting to share information with all new parents, and families made only one visit to the nursery before their child started. Through the series of meetings and visits during Ben's transition into school, we were not only able to share information and discuss what to expect in terms of provision and support, but also the staff were able to observe Ben with members of his family, particularly the strategies they used to involve him in activities and the level of language they used with him. They learnt what they could expect of Ben when he started.

### **Conclusion**

Transition planning can help families to develop their expectations of their child starting school. It can help them develop a clearer understanding and extend their experience so they are more likely to have positive outcomes to their expectations. In this case study, both the school and the family recognised the benefits of focusing on parents'/carers' perspectives at this time. It can help families to learn more about what is likely to happen so feel more confident about the future for their child. As Ben's mother concluded:

*I had a very positive experience, with his transition, and I think a lot of it was down to the support that I received and the transition work that was done. Without that, I would probably still be floundering, and he may not have been in nursery. I may have thought I will just leave him another year and see what he is like when he is four, but I made the move, and he has gone into mainstream and he is enjoying it.*

*For further information about the findings of this study please contact me by email – [fran.russell@talk21.com](mailto:fran.russell@talk21.com)*

### **References and further reading**

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## Partnership Working with Parents of Children who have Profound, Multiple Learning Difficulties in Herefordshire

By Richard Aird, Head, Barrs Court School

*in association with Tracy Goode (Teaching Assistant with responsibility for Augmentative Communication), Jenny Gittens (Teaching Assistant with responsibility for Early Thinking Skills) and Mike Ball (Head of Further Education)*

Barrs Court School is a secondary phase school catering for pupils aged 11–19 years who have severe, profound and multiple learning difficulties. The school also has a significant percentage of pupils who have complex, moderate learning difficulties who, in the main, have failed to thrive in, or who have been excluded from, mainstream education. The school serves the whole of the county of Herefordshire and is currently over-subscribed, with 57 pupils on roll in accommodation designed for 40. Only six pupils on roll at the present time can be described as having profound and multiple learning difficulties, but this number is anticipated to rise significantly. There are rapidly increasing numbers of children with profound and multiple learning difficulties who are being admitted to the school's primary feeder school, and who will transfer to Barrs Court School at the end of their Year 6. The school received very positive comments about the quality of its partnership working with parents during the school's Ofsted inspection in May 2004, and staff work hard to maintain good links with families who are scattered far and wide across the school's large, mainly isolated and rural, catchment area.

Practical examples of partnership working with parents are in evidence across diverse areas of school life. For example, on a local authority level, the school hosts meetings of the Herefordshire Consortium for Special Educational Needs (SEN) and the closely affiliated Herefordshire Parents' Forum, which are chaired by the deputy headteacher and headteacher respectively. Being so closely engaged in whole-authority SEN issues in this way helps promote good levels of awareness within the school about the holistic needs of children who have SEN and disabilities. Additionally, it enables the school to advocate on behalf of parents, families and children.

This community role also helps to ensure that at least one special school in the authority enjoys an extended, pivotal role within local SEN provision. The most recent service facilitated via this community role has been the establishing of an SEN and Disability Question Time so that parents may raise questions about the holistic needs of their children with senior figures from the local authority. Inevitably, it is the parents of children who have the most profound and complex needs who have the most questions because, sadly, it is often the case that the greater the need, the poorer the support provided.

Although the school has no designated budget with which to fund out-of-school provision, staff members volunteer their services free of charge in order to provide weekly out-of-school clubs. These currently include: a bronze and silver Duke of Edinburgh Award club; drama club; trampoline and rebound therapy club; accredited sign and sing club; and a sensory club. Parents and siblings often join pupils in these after-school clubs, and parents often report their appreciation of being able to share these activities with their children.

Other out-of-school hours partnership working includes support for augmentative communication, which is again provided voluntarily by staff members who have a specific expertise in this area. Ensuring that communication strategies are devised and implemented in partnership with parents is of vital importance, as is the first-hand knowledge which staff members gain about how different families interact with their profoundly disabled children. Home support has been successfully used in promoting the use of augmentative communication devices and in the use of symbolic communication systems such as the Picture Exchange Communication System (PECS).

Regular partnership working in pupils' homes helps overcome barriers which parents sometimes claim inhibits their ability to engage in discussions with diverse professionals. It also helps to ensure that intervention strategies are manageable within the home, which is essential for securing consistent, holistic, 24-hour provision.

The school regularly supports parents in order to advocate the needs of their children during multi-agency clinics, and this is one area of support in which parents routinely ask for assistance, particularly from teaching assistants. Constantly having to meet with a diverse range of specialists is not an easy task, especially for parents who are often weary from providing round-the-clock care and emotionally fraught from coping with the health scares their children frequently present. In a typical year, the parents of pupils who have profound and multiple learning difficulties can be required to meet with anything up to 20 different specialists, who can include paediatricians, orthopaedic surgeons, physiotherapists, occupational therapists, wheelchair technicians, dieticians, etc. Having to explain, over and over again, the same contextual information about their child's condition can be extremely debilitating for some parents, and school representatives are often asked to undertake this task by parents. They are also asked, on occasion, to challenge professional decisions that parents find unacceptable, but sometimes lack the confidence to question personally.

As well as supporting parents in multi-agency meetings, staff members will accompany parents on their visits to post-school venues in response to a parental request for a second opinion at such an emotional time. On other, sadder occasions, such as when a child's life

has become time limited because of a degenerative condition, the bond between staff and parent has been even stronger, and the mutual support such bonding has provided has helped enable both staff and parents cope with the tragedy of planning for a child's inevitable death.

A final example of partnership working facilitated in recent years has been the practice of employing parents of pupils who attend the school as teaching assistants – not to work with their own child, of course, but as bone fide members of the workforce in their own right, supporting pupils in other classes where their wealth of knowledge and skill readily enhances classroom practice. At the current time, the school employs three mothers of pupils who attend the school. Employing parents in this way is believed to promote actively an ethos that is properly child- and family-centred, as befits a special school.

Although there is no such beast as a 'typical' parent of a child who has profound and multiple learning difficulties, the highly specialist caring role demanded of such parents is common to all. The family life of affected families is also inevitably governed by the need to care for their profoundly disabled family member, often in the face of insufficient support from statutory agencies.

The severe, profound and multiple learning difficulties school can do much to promote child-centred approaches within local authority provision and to lead by example. At Barrs Court School, we hope we are beginning to provide such a lead within our own authority.

**Richard Aird**  
**Headteacher**  
**Barrs Court School**  
**Hereford HR1 1EQ**

The editor of the next PMLD LINK is

## **Rob Ashdown**

**The copy date for all articles, information and news for the Winter issue is the 1st October 2005 and the focus is on 'Meaningful Involvement'.**

Articles can be long or short and they are welcomed from carers or professionals alike – we value YOUR experience and views. Please contact us if we can help you in any way. If you have any picture or photos to include we would love to see them (providing we have permissions).

Please send contributions to: Rob Ashdown, St Lukes School, Grange Lane North, Scunthorpe, N. Lincs DN16 1BN  
 Tel: 01724 844 560 [c.ashdown@ntlworld.com](mailto:c.ashdown@ntlworld.com)

## **Parents as Research Partners Working Together to Explore Family Experiences of their Induction to a Residential Special School**

By Sally Conway (Head of Family Services), Sue Powell (Family Support Worker) and Teresa Whitehurst (Research and Development Officer), Sunfield School

### **Introduction**

Sunfield is a 52-week, residential school for children between the ages of 6 and 19 years with profound and complex autism. Sunfield works from a family-focused ethos, and has developed its services to reflect the needs of families. These needs were, in previous years, identified using a series of family surveys which were facilitated by an independent research consultant (Carpenter and Woodgate, 1999; Carpenter, Conway and Woodgate, 2003). However, following the final survey in 2002, the independent consultant suggested that surveys as a research tool were no longer an effective method of hearing the family voice, and that this survey should be seen as a catalyst for exploring future issues in greater depth using an alternative methodology.

In 2004, a research project to look at a specific aspect of Family Services was devised in place of the usual survey. The focus of the research was to explore the experiences of families at the point their child came to be resident at Sunfield and how the organisation supported them. The Project Management Team comprised the director of research/chief executive, head of family services and research and development officer. Their task was to co-ordinate the project, liaise with the Parent Advisory Group (PAG), co-ordinate and analyse data, and liaise with the independent research consultant.

### **Model**

The research used as its basis a model developed by Dr Fran Russell (2004) which adopted a participatory approach. A PAG was formed which comprised three parents who had been invited to ensure every aspect of the research was rooted in the family perspective. The three parents forming the PAG were selected on the basis of their availability and their proximity to Sunfield. (As a national provision, it was felt that PAG membership would be too great a burden for families who resided any great distance from school.) The collaboration with parents as research partners ensured that parents led the focus of this family based research.

### **A transdisciplinary approach**

A whole-organisation approach was adopted in

order to encourage staff participation from all departments. An informal information session was held to provide details of the project and the level of involvement required. Initially, the project identified the need for 10 researchers. Following the information session, 11 staff volunteered and were recruited as researchers. This group represented a cross-section of many departments within Sunfield, including Care, Education, Health, Family Services and Outreach. Training was provided in the form of a workshop which delivered a session on appropriate research methods, role play to provide an opportunity for practising interview techniques and an afternoon seminar with Dr Fran Russell illustrating the application of the model we were to use.

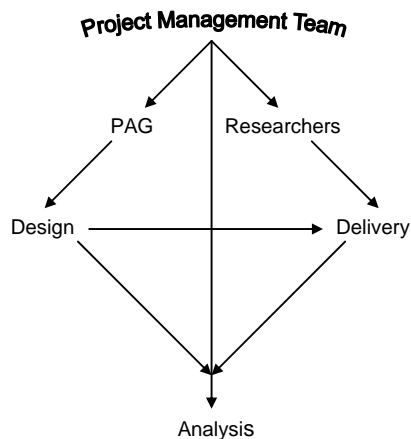
### **Research scholarships**

Sunfield Research Institute operates a system of research scholarships to enable all staff to apply for funding and support to conduct research. It was this scheme which facilitated the release of staff from their regular duties for this project.

### **Structure**

Drawing these methodological strands together provided the following structure (see Figure 1 on the next page).

## Research design



**Figure 1: Structure and roles of the research team**

The question posed by the organisation was: 'How is the Induction Process for Families?' The PAG was charged with the task of designing open-ended questions that probed specific areas of the developing induction process. Drawing on their own experiences, the focus areas they identified were:

- Parents' most powerful memory of that time
- The most helpful aspect of the induction for parents
- The least helpful aspect of the induction for parents
- What gave parents the most confidence
- Whether the process meet the needs of the whole family
- The appropriateness and usefulness of the 'link family' system
- Any alterations/amendments to the process.

A decision was taken to undertake face-to-face, semi-structured interviews with families, as opposed to telephone interviews, due to the emotional nature of the subject. Although this is a more labour-intensive and time-consuming method of collecting data, it was felt that families should be allowed time to process their thoughts and feelings in a relaxed environment. For this reason, interviews were conducted in the family home or in the Family Centre at Sunfield, dependent upon the family's preference.

## Delivery

All families were invited to participate in the

research project. Out of the 65 families to whom the questionnaire was sent, 20 responded, giving a response rate of 31%. Each family was then matched to a researcher who had not previously worked with them or their child to ensure impartiality. The researcher, in turn, was linked to either the research officer or a senior research assistant, both of whom were experienced in interview techniques. Although this process seemed relatively straightforward, the logistics and practicalities of this three-way match, together with the geographical constraints of the family homes, was extremely complex.

## Data collection

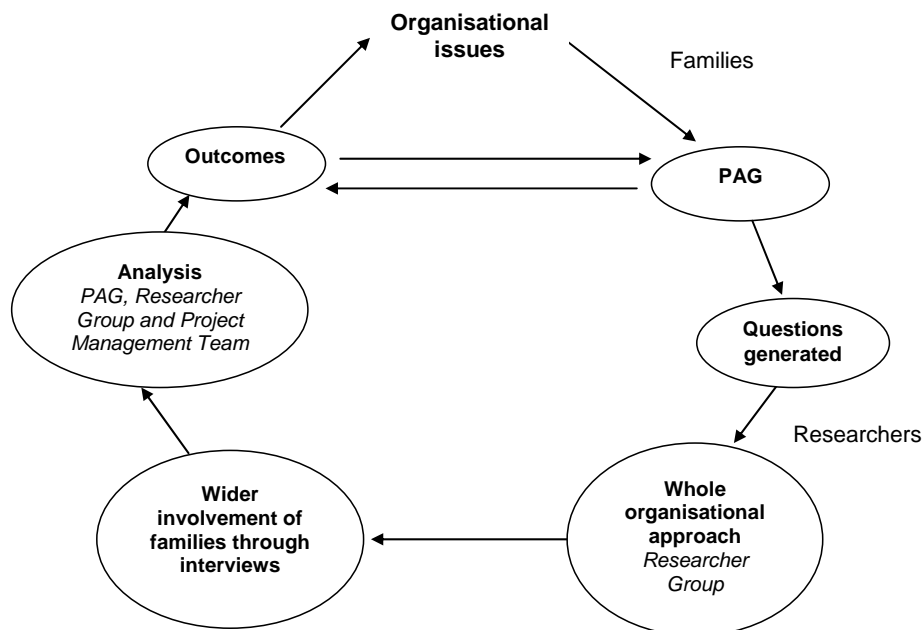
All interviews were tape recorded with permission from the family, and written notes were taken by the observer researcher. The interviews were then transcribed and sent to families for verification or alteration as required. Changes were made to only two transcripts, and these were to contextualise the conversation, as opposed to changing the contents of the interview.

## Analysis

A framework for analysing the transcripts was developed by the Project Management Team to ensure the cohesion of analysis between the stakeholder groups (Project Management Team, PAG and Researcher Group). Each group took all transcripts, and used the framework to identify consistent themes emerging from the families' accounts. The validity of this data was strengthened not only by the triangulation method employed, but further through external scrutiny via the independent research consultant. This enabled the individual strands generated by each stakeholder group to be consolidated to provide outcomes and action points.

A final meeting with the PAG to corroborate, from a parents' perspective, the validity of the outcomes and action points drawn from the stakeholder groups' analyses by the Project Management Team, ensured that the whole process remained rooted in the family perspective, whilst answering an organisational need (see Figure 2).

## Feedback from the PAG and Researcher Group about their research experience



**Figure 2: Cycle of the research partnership**

Separate meetings were arranged to speak to the PAG and the Researcher Group to gain an insight into their experiences of this unique approach to the research.

### **Researcher Group feedback**

Researchers felt this project gave them an opportunity to meet families with whom they had had no previous contact. The overall feedback from the group identified the project as being a positive and beneficial experience, which contributed to their continuing professional development. The impact of families' experiences upon the researchers differed according to their profession. For example, one researcher commented that the family that she had interviewed had given her a privileged insight into a world to which she would not have otherwise been party. This gave her a greater appreciation of the 'black hole' and state of despair that many families have travelled through by the time they reach Sunfield. For many researchers, this was a unique opportunity to gain a totally different perspective and understanding of the families to that which they would normally encounter.

Researchers felt that reflection upon such a difficult and emotional time led participants to dwell upon their situation, and it was often

difficult for the researcher to bring the focus of the interview back on track. Transcription of the tape-recorded interviews was reported to be a tedious task. This was exacerbated as participants' voices were sometimes clouded with emotion and became incoherent, which resulted in researchers spending a great deal of time clarifying the tape. In addition, the distress of the families remembering that difficult time in their lives made some researchers feel uncomfortable.

Training provided to researchers was seen as crucial to the process, and gave individuals confidence to engage families and conduct interviews. However, due to the difficulties encountered in matching professionals to families, some felt they would have benefited by conducting additional interviews which would have given more opportunity for them to develop their skills further.

Involvement of researchers in the whole process was a key feature in the methodology. The researchers reported the importance of the collaborative and supportive nature of the group culture which was created by the research project. This gave them the opportunity not only to interact with families, but also to experience a transdisciplinary element which

fostered new relationships between organisational members.

Feedback from the researchers suggested that it would have been beneficial for some parents to have received the questions before the interview. They felt this would have enabled those parents for whom the experience was traumatic, or those for whom there had been a significant time lapse between induction and interview, to have understood fully the implications of the questions. One member of staff reported that the research had impacted upon her normal work commitments, in spite of the provision of full support and cover to ensure that such problems were not encountered.

### **PAG feedback**

Parent advisors felt that the research process had given them time to reflect upon their own experience of the induction process and, through reading the transcripts, they identified that many of the undertones were similar to their own experience. Being part of the process enabled them to feel that they were in some way giving something back to Sunfield, and all felt that they had enjoyed both the process and the opportunity to be involved. In order to

manage the volume of data, the PAG felt that the opportunity to read through the transcripts prior to the analysis meeting would have been useful. During the meeting, the coding within the analysis framework was observed to be difficult to adhere to and was subsequently replaced by written note form. They offered no alternative means of being involved in the process and were happy with the level of involvement, which had not been perceived as tokenistic.

### **Outcomes and action points**

In order to ensure that the family influence impacted upon organisational activity, an action plan was designed to take forward the outcomes of this research project.

### **Conclusion**

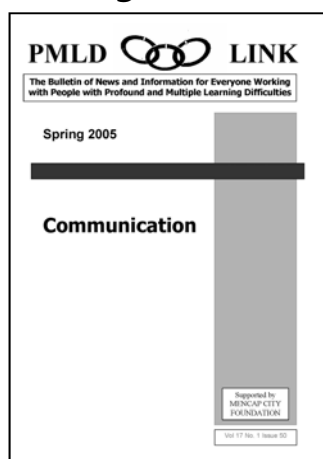
This piece of small-scale research clearly demonstrates the capacity for parents as researchers (Carpenter, 1997). They not only contributed to the research process, but led (e.g. through question formulation), analysed (e.g. through transcript analysis) and evaluated (e.g. by corroborating outcomes), thus making them true and equal research partners. For too many years, families of children with disabilities have had research inflicted upon them. The partnership approach to research is liberating for both parents and researchers. It enables their voices, their views and their aspirations to be heard and listened to, and their outlooks to broaden the traditional research perspective.

**Sue Powell, Sally Conway & Teresa Whitehurst**  
Sunfield  
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Worc's  
DY9 9PB Tel: 01562 881312

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# **INTERCONNECTIONS ELECTRONIC BULLETIN ABOUT CHILDREN WITH DISABILITIES / SEN**

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20. **Your news, information and events are welcomed!**

### **1. About this Electronic Bulletin**

It comes from Peter Limbrick, in Interconnections. Peter is an independent consultant to statutory services in the field of babies and children with disabilities / SEN.

**The Electronic Bulletin** goes free to over 3,900 people in all parts of the UK and Ireland and then finds it way into many other networks and countries. The Interconnections electronic address list includes people from health, education and social services, the voluntary and private sectors, parent organisations, research organisations, campaign offices, etc. People who receive the bulletin are welcome to forward it to their own colleagues and networks and to use the information in newsletters and bulletins as long as the Interconnections electronic bulletin is acknowledged.

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## Research

### Major survey of people with learning difficulties: final report to be published July 2005

The Department of Health have commissioned BMRB Social Research to conduct a major survey of people with learning difficulties in England. The survey conducted is in a partnership/consortium arrangement including Central England PeopleFirst and the Institute for Health Research at Lancaster University.

Fieldwork for the survey was completed in October 2004 and a report on the findings will be published in July 2005

The aims of the survey are:

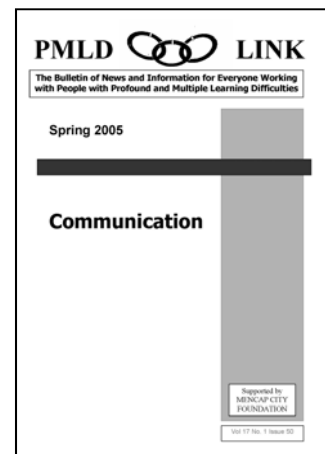
to establish from people with learning difficulties themselves what their whole lives are like including where they live and with whom, what they do during the day, and what their needs, wants and aspirations are

to describe current use of services by people with learning difficulties, as well as their views on the services, to help establish what are the gaps between what is currently provided for people with learning difficulties and what they would like

If you have any difficulty in downloading these reports you can request a hard copy of the reports by contacting Michael Sweetland at the address below:

Department of Health, Statistics Division  
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Elephant & Castle  
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### **Rob Ashdown**

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Articles can be long or short and they are welcomed from carers or professionals alike – we value YOUR experience and views. Please contact us if we can help you in any way. If you have any picture or photos to include we would love to see them (providing we have permissions).

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Tel: 01724 844 560 [c.ashdown@ntlworld.com](mailto:c.ashdown@ntlworld.com)



## YOU & ME Yoga Modular Programme for Professionals

YOU & ME Yoga has been designed specifically for people with learning disabilities - including those with profound and complex needs - to improve their quality of life. Practice helps to increase: health, mobility, physical dexterity, coordination, sensory-awareness, concentration, adaptive behaviour, communication, social skills and self-confidence.

YOU & ME Yoga is a highly specialised and sophisticated system. It enables the therapist to arrange programmes precisely to the needs of individuals and groups with learning disabilities of all ages, allowing them to get the very most from their yoga experience.

The development of a unique system of sound, colour coding and recording, and the provision of a comprehensive set of material resources mean that, once learnt, it is very simple to use. Thus enabling professionals, personnel and parents to work together in yoga with people with learning disabilities. A full description and samples of these materials, and the training can be viewed on: [www.youandmeyoga.com](http://www.youandmeyoga.com)

### Programme consists of 4 one day modules, assessment and external verification:

#### Module 1: Looseners

- Assessment and Joint Loosener techniques
- Variations of Looseners for special needs
- The Looseners and related Postures

#### Module 2: Relaxation

- Relaxation techniques for people with special needs and their trainers

#### Module 3: Postures

- Practice, theory and assessment of the Yoga Postures
- Selecting sequences of Whole-Body-Movement for contrasting abilities
- Variations of the Postures for constrating abilities

#### Module 4: Breathing

- Breathing techniques for people with special needs and their trainers

### Training:

Training is held at the Yoga Therapy Centre, London, nr Kings Cross and Angel stations. Training is also available to run in-house at your own venue for groups of 4 - 12 people.

### Advantages of YOU & ME Yoga:

- it is inexpensive to run
- is of personal benefit for all participants
- empowers all participants to learn and share yoga together!

Claire Hay, Greenwich Teaching PCT, states: "I think Maria is providing a wonderful service and has found a good way of making yoga accessible to all."

**Contact: Maria Gunstone t. 0870 172 0188**  
e: [maria@youandmeyoga.com](mailto:maria@youandmeyoga.com) [www.youandmeyoga.com](http://www.youandmeyoga.com)



# NEWS, PUBLICATIONS AND RESOURCES

## RESOURCE

### Epilepsy and Learning Disabilities

A training pack to aid teaching on epilepsy and its management

Mary Codling, Nicky MacDonald, Fiona Simpson and Barbara Chandler, Berkshire Healthcare NHS Trust

Epilepsy and Learning Disabilities provides trainers with the material to deliver training to care and residential staff on epilepsy and its management, particularly relating to epilepsy in people with learning disabilities. The pack's flexibility allows it to be used by a wide range of organisations.

The training is presented in two sessions:

- Session A: Introduction to epilepsy
- Session B: Administration of rectal diazepam (because this is an invasive medical procedure, Session B must be taught by a qualified nurse)

The pack offers step-by-step instructions, all the training materials needed to deliver the training and two videos, The Right Stuff: facts and first aid for epilepsy and Rectal Diazepam.

Of particular interest to: residential care homes, education facilities, NHS establishments, social services, nurses, independent sector and local authorities

Format: ringbound resource (pp) and two Epilepsy Association videos (25 minutes and 20 minutes)



**Price:** £175.00

**Code:** AF4

**ISBN:** 1 84196 129 9

## MENCAP

*Understanding learning disability*

<http://www.mencap.org.uk/pmld>

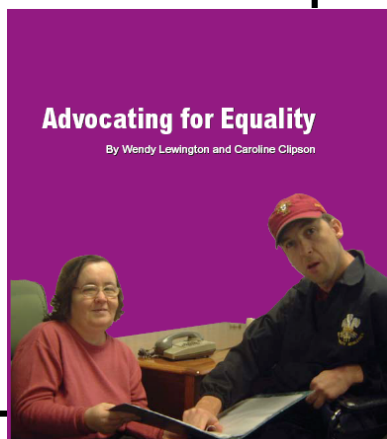
### Focus on People with PMLD

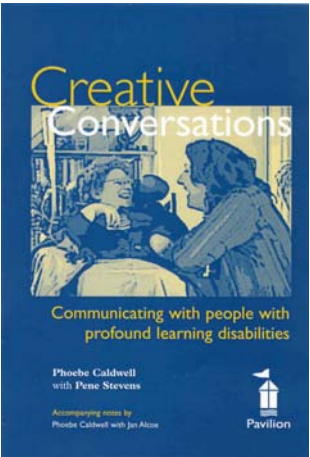
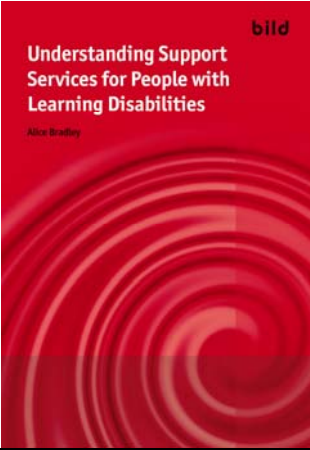
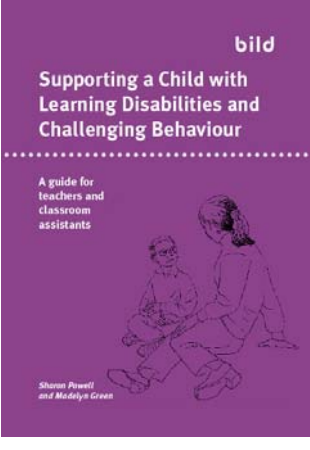
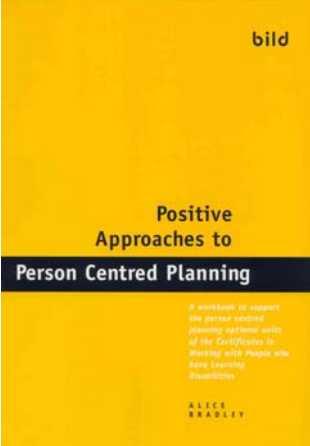
A new area of the Mencap website focusing on people with profound and multiple learning difficulties.

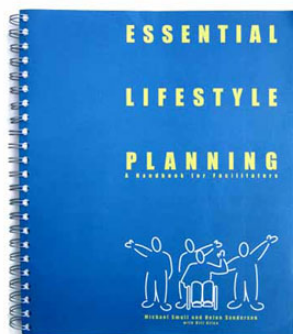
Also on the website is:

['Advocating for Equality'](#)

A report based on a survey of the current levels of advocacy provision for disabled people in England.



 <p><b>Creative Conversations</b> Communicating with people with profound learning disabilities Phoebe Caldwell with Pene Stevens Accompanying scenes by Phoebe Caldwell with Jen Alton Pavilion</p>	<p><b>Author (s):</b> Phoebe Caldwell with Pene Stevens</p> <p><b>Publisher:</b> Pavilion</p> <p><b>ISBN:</b> 184 196 1345</p> <p><b>Pub Date:</b> 2005</p> <p><b>Price:</b> £115</p>	<p><b>Creative Conversations</b> <b>Communicating with people with profound learning disabilities</b></p> <p>This new training resource seeks to bridge the gap in the range of currently available material on the use of Intensive Interaction. The video shows how Intensive Interaction is used to find ways of communicating with people who have multiple and profound learning difficulties, enabling them to express their feelings, as well as their needs.</p>
 <p><b>Understanding Supportive Services for People with Learning Disabilities</b> Alice Bradley bild</p>	<p><b>Author:</b> Alice Bradley</p> <p><b>Publisher:</b> BILD</p> <p><b>ISBN:</b> 1 904082 94 7</p> <p><b>Pub Date:</b> 2005</p> <p><b>Price:</b> £20.00</p> <p><b>Members Price:</b> £18.00</p>	<p><b>Understanding Supportive Services for People with Learning Disabilities</b></p> <p>The book is intended for managers and senior practitioners who want to continue their professional development.</p> <p>The book should also be of interest to senior staff and managers who are preparing for the Learning Disabilities Awards Framework (LDAF) Higher Professional Diploma (Level 4) Unit 1: Understanding Learning Disability Services and studying S/NVQ at Level 4.</p>
 <p><b>Supporting a Child with Learning Disabilities and Challenging Behaviour</b> A guide for teachers and classroom assistants Sharon Powell and Madelyn Green bild</p>	<p><b>Author (s):</b> Sharon Powell &amp; Madelyn Green</p> <p><b>Publisher:</b> BILD</p> <p><b>ISBN:</b> 1 904082 88 2</p> <p><b>Pub Date:</b> 2005</p> <p><b>Price:</b> £5.00</p> <p><b>Members Price:</b> £4.50</p>	<p><b>Supporting a Child with Learning Disabilities and Challenging Behaviour</b></p> <p>Some children use challenging behaviours as a way of communicating their feelings. Finding the appropriate response to behaviours that may be difficult to manage is not always easy. This guide is a practical introduction to supporting a child with a learning disability and challenging behaviour for teachers and classroom assistants. It defines challenging behaviour, identifies the factors that make it possible and includes simple and effective strategies that may help and a question and answer section dealing with challenging situations.</p>
 <p><b>Positive Approaches to Person Centred Planning</b> A workbook to support the person-centred planning process in working with people with learning disabilities Alice Bradley bild</p>	<p><b>Author:</b> Alice Bradley</p> <p><b>Publisher:</b> Bild</p> <p><b>ISBN:</b> 1 904082 86 6</p> <p><b>Pub Date:</b> 2004</p> <p><b>Price:</b> £12.00</p> <p><b>Members Price:</b> £10.80</p>	<p><b>Positive Approaches to Person Centred Planning</b></p> <p>Workbook</p> <p>Contents include:</p> <ul style="list-style-type: none"> <li>• An introduction to person centred planning</li> <li>• The process of person centred planning</li> <li>• Different styles in person centred planning</li> <li>• Responding to the challenges of person centred planning</li> </ul>



**Author (s):** Michael Smull,  
Helen Sanderson,  
Bill Allen

**Publisher:** Helen Sanderson  
Associates

**ISBN:** 1898385335

**Pub Date:** 2001

**Price:** £28.95

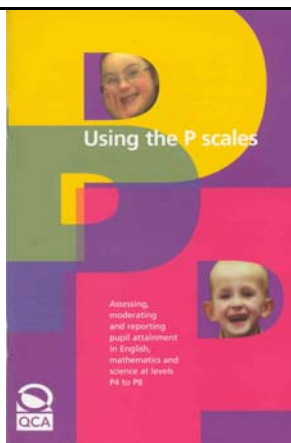
### Essential Lifestyle Planning: A Handbook for Facilitators

Essential lifestyle planning is a guided process for learning how someone wants to live and developing a plan to help make it happen. An essential lifestyle plan is useful for anyone where it is helpful to:

Discover what is important to a person in everyday life; and

Identify what support the person requires and any issues of health or safety (from the perspective of the person)

Describe what you have learned in a way that is easily understood by those who will enable the person to get what is important to them



**Author (s):** QCA

**Publisher:** QCA

**ISBN:** N/A

**Pub Date:** 2005

**Order ref:** QCA/05/1589

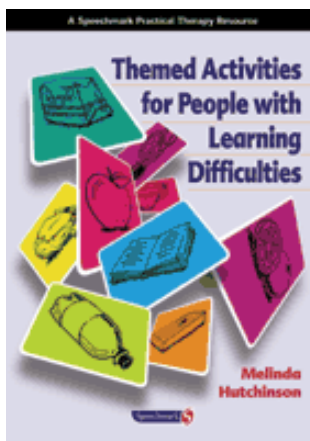
**More Information:** [pscales@qca.org.uk](mailto:pscales@qca.org.uk)

### Using the P Scales

Who is it for?  
Teachers in mainstream and special schools, special educational needs coordinators, assessment coordinators, headteachers.

What it is about?  
This document introduces the P scales and outlines ways of using them.

What is it for?  
It supports teachers in making judgements about pupils' attainment below level 1 of the national curriculum



**Author:** Melinda  
Hutchinson

**Publisher:** Speechmark

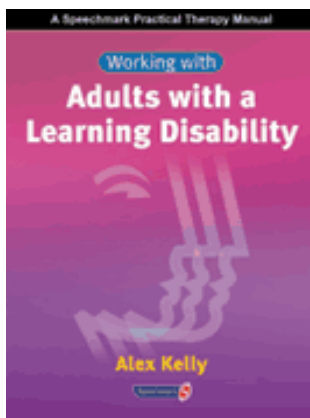
**ISBN:** 0 86388 307 9

**Pub Date:** 2005

**Price:** £36.50

### Themed Activities for People with Learning Difficulties

User-friendly and practical, this is an excellent resource for all professionals looking to run creative sessions with people with profound and complex learning difficulties. Using a selection of twenty everyday objects, it provides resource materials, ideas and flexible structures to extend and complement professionals' existing approaches.



**Author:** Alex Kelly

**Publisher:** Speechmark

**ISBN:** 0 86388 413 x

**Pub Date:** 2005

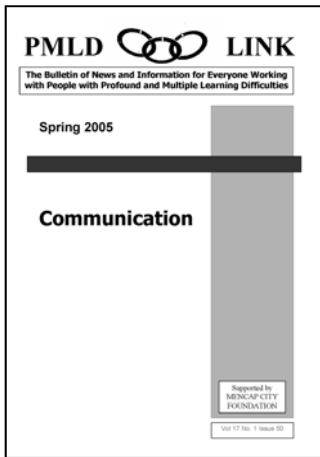
**Price:** £41.95

### Working with Adults with Learning Disability

A comprehensive and practical resource for all speech & language therapists and students, *Working with Adults with a Learning Disability* covers all aspects of working with this client group, including:

An introduction to learning disability  
Assessment of the client and their environment  
Profound and multiple disability  
Challenging behaviour  
Augmentative and alternative communication  
Social skills  
Dysphagia  
Staff training and working in a community learning-disability team

 <p>A Manual for the <b>Early Years</b> SENCO</p> <p>Collette Drifte</p>	<p><b>Author:</b> Collette Drifte</p> <p><b>Publisher:</b> Paul Chapman Publications</p> <p><b>ISBN:</b> 1 4129 1026 9</p> <p><b>Pub Date:</b> 2005</p> <p><b>Price:</b> £16.99</p>	<p><b>A Manual for the Early Years SENCO</b></p> <p>Are you a new SENCO? Are you a busy SENCO juggling your SEN role with your existing job? Could you use some time-saving ideas and practical advice? Starting with a look at the role and responsibilities of a SENCO, this book covers all areas of the job from supporting children and colleagues to working with parents and outside agencies. An entire section on planning will help you timetable your year and break your workload down into manageable chunks.</p>
 <p>the SEN series <b>Profound and Multiple Learning Difficulties</b> CORINNA CARTWRIGHT and SARAH WIND-COWIE</p>	<p><b>Author (s):</b> Corinna Cartwright &amp; Sarah Wind-Cowie</p> <p><b>Publisher:</b> Continuum</p> <p><b>ISBN:</b> 0 8264 7836 0</p> <p><b>Pub Date:</b> 2005</p> <p><b>Price:</b> £7.99</p>	<p><b>Profound and Multiple Learning Difficulties</b></p> <p>This invaluable guide equips teachers and trainers with practical tips and strategies for teaching children with profound and multiple learning difficulties. Engaging and informative, the authors provide advice on areas such as the daily management of pupils with PMLD, learning environments, dealing with problem behaviour and getting families involved.</p>
 <p>Foundation for People with Learning Disabilities</p> <p><b>Shaping the Future Together</b></p> <p>A strategic planning tool for services supporting people with learning disabilities</p>	<p><b>Author:</b> Foundation for People with Learning Disabilities</p> <p><b>Publisher:</b> Foundation for People with Learning Disabilities</p> <p><b>ISBN:</b> 1 903645 60 3</p> <p><b>Pub Date:</b> 2005</p> <p><b>Price:</b> £12.50</p> <p><b>Tel. No.</b> 0207 8031100</p>	<p><b>Shaping the Future Together Pack</b></p> <p>A pack to help organisations develop services and approaches that respond to what people with learning disabilities say they want.</p> <p>It supports person-centred approaches by providing a systematic link between individual and strategic planning. It enables planners and managers to obtain an overall picture of what individuals with learning disabilities want. They can subsequently make sure that the appropriate opportunities and support are developed to meet those people's wishes and needs.</p>
 <p><b>Inclusive Play</b> Practical Strategies for Working with Children aged 3 to 8</p> <p>Theresa Casey</p>	<p><b>Author:</b> Theresa Casey</p> <p><b>Publisher:</b> Paul Chapman Publications</p> <p><b>ISBN:</b> 1 4129 0243 6</p> <p><b>Pub Date:</b> 2005</p> <p><b>Price:</b> £18.99</p>	<p><b>Inclusive Play: Practical Strategies for Working with Children Aged 3 to 8</b></p> <p>Do all the young children in your setting have an opportunity to engage in meaningful play? By making practical suggestions and using tried-and-tested approaches, this book shows you how to help all the children in your care to feel included and involved in play opportunities.</p>



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#### **British Institute of Learning Disabilities**

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DY10 1JL

Tel. 01562 723025

E-mail: [learning@bild.org.uk](mailto:learning@bild.org.uk)

website: [www.bild.org.uk](http://www.bild.org.uk)

#### **Catalyst Education Resources Ltd**

1A Potters Cross  
Wootton, Bedfordshire MK43 9JG, U.K.

Further details:

Tel. 01234 764 108

E-mail: [FloCatalyst@aol.com](mailto:FloCatalyst@aol.com)

Web: [www.cerl.net](http://www.cerl.net)

#### **Sunfield PDC**

Clent Grove, Clent,

Nr. Stourbridge,

West Midlands

DY9 9PB

Tel. 01562 883183

E-mail: [Sunfield@sunfield.worcs.sch.uk](mailto:Sunfield@sunfield.worcs.sch.uk)

#### **Concept Training**

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Morecambe,

Lancashire LA4 6BT

Tel. 01524 832 828

Fax: 01524 832 852

E-mail: [info@concept-training.co.uk](mailto:info@concept-training.co.uk)

#### **University College Northampton**

Further details:

Centre for Professional Development in  
Education

Tel. 01604 892695

Fax: 01604 714635

E-mail: [cpde@northampton.ac.uk](mailto:cpde@northampton.ac.uk)

#### **Equals**

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Email: [admin@equals.co.uk](mailto:admin@equals.co.uk)

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### CATALYST

Richard Hirstwood of *Hirstwood Training*  
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### EQUALS BEST PRACTICE WORKSHOPS

#### **INTENSIVE INTERACTION**

7<sup>th</sup> October 2005 London

**Dave Hewett; Educational Consultant**

#### **USING A TRAMPOLINE FOR REBOUND THERAPY**

25<sup>TH</sup> and 26<sup>TH</sup> November 2005 Newcastle upon Tyne

**Chris Rollings; Deputy Head Teacher,**

### Concept conference

Exploring the benefits of a  
multi-sensory approach

**8th & 9th October 2005**

*West Bromwich, West Midlands*

<b>SUNFIELD PDC</b>		
<b>COURSE DETAILS</b>	<b>COURSE NO.</b>	<b>DATE(S)</b>
Music Therapy for Children with S.E.N. <i>Led by: Julie Wylie &amp; Assisted by Louise Shand, Music Therapists</i>	PDC/022/05	28 Sept
PowerPoint for PMLD (A Hands on Course) – 2 separate days <i>Led by: Martyn Maltby, Deputy M.D - Liberator Ltd</i>	PDC/023/05	3 Oct
	PDC/024/05	4 Oct
Sherborne Developmental Movement 'Taster Day' Introductory Basic Course <i>Led by: Cyndi Hill, Sherborne Consultant</i>	PDC/026/05	10 Oct
Intensive Interaction <i>Led by: Dave Hewett, Freelance Trainer &amp; Consultant</i>	PDC/027/05	11 Oct
Reconfiguring Special Schools to become generic and specialist <i>Led by: Chris Darlington &amp; Rob Ashdown</i>	PDC/030/05	7 Nov
The Supporters Club <i>Led by: Sally Conway, Head of Family Services – Sunfield Elizabeth Atfield, Training Officer (Family and Education) - autism west midlands</i>	PDC/031/05	8 Nov
Teaching Assistant's Conference – Various Disabilities – 2 separate days (ADHD, Autism, Downs Syndrome) <i>Led by: Dr Paul Hutchins – Child Development Unit &amp; Children's Hospital Education Research Unit – The Children's Hospital, Sydney, Australia + Barry Carpenter, Principal &amp; Chief Executive, Sunfield &amp; Nick Logan, Consultant Psychologist, Sunfield</i>	PDC/033/05	15 Nov
Early Childhood Intervention – European Conference <i>Led by: National &amp; International Speakers</i>	PDC/80950	28 & 29 Nov

<b>Concept Training</b>		
Understanding the Multi-Sensory Concept	Queens Hotel, Dundee	<b>August 31, 2005</b>
	Adelphi Centre, Glasgow	<b>September 1, 2005</b>
	Sevenoaks Hotel, Carlow	<b>September 7, 2005</b>
	Linton Lodge Hotel, Oxfordshire	<b>September 14, 2005</b>
	The Ibis Hotel, Euston	<b>September 15, 2005</b>
	Dylan Thomas Centre, Swansea	<b>September 28, 2005</b>
Sensory Differences and the Role of Positive Touch	The Portland Hotel, Edgbaston	<b>6 October 2005</b>
	Grangemoor Hotel	<b>30 November 2005</b>
	The Ibis Hotel, Euston	<b>8 December 2005</b>
Intensive interaction	<b>Dundee</b> , Queens Hotel	<b>12th September</b>
	<b>Glasgow</b> , Adelphi centre	<b>13th September</b>



<b>BILD</b>		
<b>Creative Communication Code</b>	14 Oct 2005	Kidderminster
	16 Nov 2005	Warrington
<b>Meeting the needs of people with profound learning disabilities</b>	3 Oct 2005	Kidderminster
	12 Dec 2005	London
<b>An introduction to using computers to support adults with a learning disability</b>	7 Sept 2005	Abingdon
	1 Dec 2005	Abingdon
<b>Sexuality and personal relationships for people with learning disabilities</b>	20 Oct 2005	Leeds
	14 Nov 2005	Kidderminster
<b>Inappropriate sexual behaviours: children and young people with learning difficulties</b>	17 Oct 2005	London
	7 Nov 2005	Kidderminster
<b>Protection of vulnerable adults</b>	20 Sept 2005	Kidderminster

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Full page £20

## LONGER COURSES (with accreditation)

June 2005 update

### Master of Arts in Education

#### Understanding Severe and Profound and Multiple Learning Difficulties (EDUM028)

This module addresses the requirements of the Teacher Training Agency (TTA) National Special Educational Needs Specialist Standards. This accreditation is awarded to students completing the requirements for the three modules EDUM028, EDUM029 and EDUM040. This module is directly related to developing the competencies, knowledge, understanding and critical reflection of students who are, or planning to be Special Education Needs Teachers. The module adheres to the national TTA SEN Specialist Standards (Core and Extension Standards) and students are given opportunities and support to collate evidence to meet the standards.

For further Details: University College Northampton. Tel: 01604 892695. E-mail: [cpde@northampton.ac.uk](mailto:cpde@northampton.ac.uk)

### Supporting Learners with SLD/PMLD

During the course we will be looking in detail at the needs of learners who are known to have a severe or profound and multiple learning difficulties. They may also have other additional or associated disabilities, such as physical or sensory impairments. The course will examine topics of both a theoretical and practical nature to provide students with a greater understanding about this group of learners. Together with a broad range of strategies and approaches that can be applied to practice. The sessions will include lectures, workshop activities, discussion and some visiting speakers.

For further Details: University College Northampton. Tel: 01604 892695. E-mail: [cpde@northampton.ac.uk](mailto:cpde@northampton.ac.uk)

### AdCert, BPhil, PGCert, PGDip, MEd.

#### An Interdisciplinary Approach to Learning Difficulties (Severe, Profound and Complex)

##### *Distance education*

This distance education programme has been developed for the range of staff who work with people with severe, profound and complex learning difficulties, for example teachers and lecturers, nurses, therapists, psychologists and support staff.

It is primarily about the learning and development of children and adults with severe, profound and complex learning difficulties, particularly in the areas of cognition and communication. Education, in its broadest sense, is seen as a key topic but other areas covered include health, therapy and social care. An important central theme is interdisciplinary / multi-agency collaboration and course participants will be expected to develop and reflect on their interdisciplinary work as part of course. All the course assignments are grounded in reflective and evidence-based practice and are driven by the individual professional development needs of participants.

For further details please contact: Dr Penny Lacey, phone: 0121 414 4878 or email: [p.j.lacey@bham.ac.uk](mailto:p.j.lacey@bham.ac.uk)

### Ad Cert, PG Cert.

#### An Interdisciplinary Approach to Learning Difficulties (Severe, Profound and Complex): Challenging Behaviour Route

##### *Distance Education*

This is not a separate programme but is a route through the programme called 'An Interdisciplinary Approach to Learning Difficulties (Severe, Profound and Complex)'.

If you are primarily interested in learning difficulties and challenging behaviour you should study the following modules:

- Learning Difficulties (Severe, Profound and Complex): Communication and Behaviour
- Interventions for Learning Difficulties (Severe, Profound and Complex)
- Special Studies in Special Education (project)

Successful completion of these 3 modules will lead to Ad Cert or PGCert. If you wish to continue to BPhil, PGDip or MEd, you will study the second year modules from the main programme.

For further details please contact: Dr Penny Lacey, phone: 0121 414 4878 or email: [p.j.lacey@bham.ac.uk](mailto:p.j.lacey@bham.ac.uk)

**AdCert, BPhil, PGCert, PGDip, MEd.**  
**Multisensory Impairment (Deafblindness)**

*Distance education*

This programme enables teachers and others working in education related fields to work more effectively with learners who are deafblind (multisensory impaired).

Some students are teachers working with children or adults, but others are from social services, medical, or residential work. A one-year programme can lead to the awards of Advanced Certificate or Postgraduate Certificate.

- A two-year programme can lead to the award of BPhil, or Postgraduate Diploma.
- A two-year programme with a dissertation can lead to the award of an MEd.

Students working on BPhil or Postgraduate Diploma programmes with some additional activities can, on successful completion, be recognised as meeting the requirements of the DfES for the mandatory qualification for teachers of children with multisensory impairments.

For further details please contact: Dr Liz Hodges on 0121-414 4873 or email: [e.m.hodges@bham.ac.uk](mailto:e.m.hodges@bham.ac.uk)

**MSc and Graduate Diploma in Learning Disability Studies**

This course *is now Distance Learning only*

If you are currently working with people with a learning disability and are interested in updating and expanding your knowledge of theory and practice, this course provides an opportunity to learn alongside other experienced professionals from a wide range of backgrounds.

- Is designed for experienced professionals involved in the care of adults and children with a learning disability.
- Is a distance course, involving the use of specially-prepared texts, annual weekend schools, and local tutorial groups.
- Assesses ability through small practical assignments and a dissertation of 15,000 words based on original research.
- Can be completed in one-year (full-time) or between two and five years (part-time).
- Allows the possibility of combining modules from parallel courses on forensic mental health and child and family mental health.
- Leads to a Masters of Science degree after the completion of all assignments and the dissertation, or a Postgraduate Diploma for the completion of the assignments alone.

For further details please contact: Dr Stuart Cumella, Division of Neuroscience on 0121 414 4507 or email: [S.Cumella@bham.ac.uk](mailto:S.Cumella@bham.ac.uk)

**Postgraduate taught MSc 24-36 months months**

**Profound Learning Disability and Multi-Sensory Impairment MSc for entry in 2005**

*Distance Learning*

The course is aimed at students who personally and professionally come into contact with individuals with complex learning needs and sensory impairments, or who have a desire to gain the specialized knowledge related to this area of interest.

- To provide a unique opportunity for a wide range of people to acquire knowledge and skills to empower them to enable individuals with very complex needs to reach their full potential.
- To provide an increased knowledge and understanding of children and adults who have complex learning needs and sensory impairments.
- To enable those directly concerned with this group to advocate for the rights of the individuals concerned and work towards improving their quality of life and community presence.
- To enable this to happen by providing current information relating to cognitive, emotional, physical, sensory and social needs.
- A theoretical framework is reinforced through practice in the student's home environment/workplace.

For further details please contact: Email [pg-education@manchester.ac.uk](mailto:pg-education@manchester.ac.uk) or telephone 0161 275 3337

**Postgraduate taught PG Diploma**

**Profound Learning Disability and Multi-Sensory Impairment PG Diploma for entry in 2005**

*24 months Distance Learning*

The course is aimed at students who personally and professionally come into contact with individuals with complex learning needs and sensory impairments, or who have a desire to gain the specialized knowledge related to this area of interest.

- To provide a unique opportunity for a wide range of people to acquire knowledge and skills to empower them to enable individuals with very complex needs to reach their full potential.
- To provide an increased knowledge and understanding of children and adults who have complex learning needs and sensory impairments.
- To enable those directly concerned with this group to advocate for the rights of the individuals concerned and work towards improving their quality of life and community presence.
- To enable this to happen by providing current information relating to cognitive, emotional, physical, sensory and social needs.
- A theoretical framework is reinforced through practice in the students home environment/workplace.

For further details please contact: Email [pg-education@manchester.ac.uk](mailto:pg-education@manchester.ac.uk) or telephone 0161 275 3337

**PGCert, AdCert.**

**Early Years: Sensory and Multiple Needs—This programme begins in January**

*Distance education.*

This programme enables professionals to work more effectively with young children with sensory and multiple needs. Participants may be teachers, who may already hold a specialist qualification in visual impairment, deafness or multisensory impairment; specialist speech and language therapists; health visitors; social workers; carers or others working with young children with sensory and additional needs.

For further details please contact: Dr Liz Hodges on 0121 414 4873 or email: [E.M.Hodges@bham.ac.uk](mailto:E.M.Hodges@bham.ac.uk)

The editor of the next PMLD LINK is

**Rob Ashdown**

**The copy date for all articles, information and news for the Winter issue is the 1st October 2005 and the focus is on 'Meaningful Employment'.**

Articles can be long or short and they are welcomed from carers or professionals alike – we value YOUR experience and views. Please contact us if we can help you in any way. If you have any picture or photos to include we would love to see them (providing we have permissions).

Please send contributions to

Rob Ashdown,  
St Lukes School,  
Grange Lane North,  
Scunthorpe,  
N. Lincs DN16 1BN  
Tel: 01724 844 560  
[c.ashdown@ntlworld.com](mailto:c.ashdown@ntlworld.com)

## Postcard from Abroad

*from* Prakash Grover, Speech and Language Therapist & Trainee Psychologist, Mount Richmond Special School, Otahuhu, Auckland, New Zealand

*Mount Richmond Special School has 14 students with complex multiple needs out of a total student population of 142.*

### **Some shared wisdom...**

1. The introduction of a lemon water application on the tongue and hard palate just before feeding students with very high needs and known swallowing difficulties has shown a significant reduction in chest infections and aspiration. No empirical research has been done in our school, but anecdotal notes indicate a significant positive change. The basic essence of the approach lies in oro-motor stimulation and muscle activation before feeding the students with very high needs. Lemon water helps in the emergence of swallow reflex and stimulates the pharyngeal muscles to prepare the student for safe swallowing of food.
2. It has been consistently observed at Mount Richmond Special School that children with very high needs with swallowing difficulties, if fed more than 20 minutes at a stretch, experience fatigue and display more episodes of reflux and cough
3. The introduction of the Picture Exchange Communication System (PECS) as a strategy to reduce problem behaviour is being discussed at Mount Richmond Special School. Literature has supportive evidence regarding this. Data on frequency and ABC forms reveals that problem behaviour in non-verbal children often has communicative intent. Use of augmentative/alternative strategies like PECS fits into the positive behaviour support model, where teaching replacement skills after functional assessment of the behaviour is recommended. The use of PECS strategies presents itself as an option to the child to express his needs. Our school has been assessing the impact of the use of the system on problem behaviour. Results so far seem to be confirming a positive relationship.
4. Use of metronome instruments (which are used by musicians) to teach language to intellectually disabled students though the tones has been very encouraging. It is based on the belief that most of the students with intellectual disabilities have got right hemisphere dominance and often like music. Use of metronome and teaching students to pick up the tones and words has been tried by the Speech Language Therapist at Mount. Richmond Special school. Students seem to be picking up the discrete tones and words.

## *Report Back ....*

### **Parents as trainers... read on!**

I recently attended one of several regional events to share the outcomes of research funded by The Foundation for People with Learning Disabilities (fpld). The ***'Making Us Count' Seminar in London, Identifying and improving the mental health support for young people with learning disabilities***- was a really inspiring day. The whole event not only centred on cutting edge research within the learning disability field, but it involved the very people at the heart of it all.

Some of the young people (with learning disabilities) involved in the projects shared their experiences with us, about their learning to understand and deal with their emotions. The presentation that really hit home for me though, was one involving parents of youngsters with profound and multiple learning disabilities (PMLD). It is rare to find research centred around this group of individuals, let alone with such forward-thinking principles.

#### ***The Well-Being project: Identifying and meeting the needs of young people with profound and multiple learning disabilities and their carers.***

This piece of research was led by Maureen Phillip of White Top Research Unit, University of Dundee. Its initial focus was on how carers identify and respond to the emotional and mental well-being of their son or daughter with PMLD. One of the outcomes of this research was the development of training workshops on the Emotional and Mental Well-being of this group of youngsters, facilitated by Loretto Lambe of PAMIS. This development was the exciting bit - these training workshops were ***designed and delivered by parents*** of young people with PMLD!

The training they had developed was designed to inform parents, families, carers and front line staff and explored issues such as change and transitions, health issues, loss and bereavement and supportive therapies. Together the group had developed a very accessible workshop structure that was used for each theme. This included guided tasks, case studies (of their sons and daughters), buzz groups and discussion.

At the seminar, we heard from the parents themselves about how they developed the training materials by focusing on their area of expertise – their sons and daughters. By using their knowledge and experience, we were given some thought-provoking insights of why and how *their* youngsters expressed emotions or general well-being. These materials will soon be available from the fpld website (link below)...watch this space!

A key comment from their presentation offered a valuable reminder that really resonates with me, when thinking about the quality of my younger brother's life and in my professional role within the field.

#### ***'Stand in the shoes of the person with PMLD before you make decisions on their behalf'.***

Albeit with the best intentions (and with resources etc, etc, etc permitting) - *how well do we really do this?*

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