

PMILD



LINK

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

Summer 2004

Quality Services

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

Quality Services

Guest Editorial	Di Foxwell	2

Future Focus	Ann Fergusson	3

Getting a Life Not an Existence	Kirsty Thomson	4

Making a Difference?	Ruth Townsley, David Abbott and Debby Watson	8

Open to all – CAP referral for children with SLD/PMLD	Stephen Segal & Richard Walter	11

Key Workers are an essential part of a quality service for families	Peter Limbrick	13

Sleep Scotland <i>helps the Sleepless!</i>	Emma Vinnie and Jane Ansell	16

Health Matters	Pat Bushell, Liz Bridgman, Lucinda Harding, Daniel Marsden	19

The Electronic Bulletin	Peter Limbrick	28

News, Publications and Resources		36

Review		

Physical Interventions and the Law: Legal issues arising from the use of physical interventions in supporting children, young people and adults with learning disabilities and severe challenging behaviour	Steve Cullingford-Agnew	40

Courses and Conferences		43

Report Back		49

Conference: Communication and PMLD -What's New?	Janet Trebilcock	

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

The editor of the next PMLD LINK is Ann Fergusson.

The copy date for all articles, information and news for the Winter issue is the 1st November 2004 and the focus is on 'Assessment'.

Don't forget to send all contributions to Ann Fergusson preferably in RTF (Rich Text Format) or 'Microsoft Word' (Ann's contact details are on the next page). If you are also able to supply photographs and/or images to enhance your article please do so, but it is important that the relevant permission to publish is obtained beforehand.

As we near the end of this period of change with PMLD LINK it is important readers refer to the latest edition to keep track of who is doing what, this is particularly important since Carol Ouvry stepped down as the editor and we moved over to having rotating guest editors.

GUEST EDITORIAL

Summer 2004

Quality Services

This is the second edition of PMLD LINK produced the University College Northampton and you will no doubt have noticed we are evolving. Paul, who takes care of our production, is doing a sterling job and has ideas that will further enhance our production too. He is particularly interested in developing our 'graphics' so we are definitely 'going up market'

However both myself and the future guest editor have marvelled at the amount of hard work Carol Ouvry has put into previous editions, and yet made it flow so well. Only now are we beginning to appreciate the level of commitment it takes.

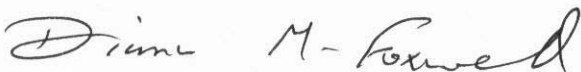
Our last edition edited by Tina Tilstone, was also a very exciting read and she had included many interesting articles.

In this issue you will find many interesting articles that are very diverse. We have research articles, personal views, and projects – all with a central theme about quality. We have also included this time an electronic bulletin that contains even more useful information.

There also seems to be quite a lot happening on the conference rounds at the moment too - take a quick peek. For some of the authors here it is the first time they have had work published and I think that is one of the great plusses of our journal, being quite small we are friendly – it is a great place to test the water for many budding writers.

Unfortunately we had a little teething problem in the last edition and feel we must print an apology. We would like to say sorry to Jesyca and her teacher – Sarah. They very kindly allowed us to print a photo of Jesyca playing with her outdoor activities in the playground that was devised by her teacher Sarah. Unfortunately we printed the wrong caption with the photo and it should have read, “**A Good Idea (From a parent)**”

I hope you enjoy the issue.



Diana Foxwell

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

Future Focus: Assessment

By Ann Fergusson

The theme of our next edition is 'Assessment'. This is a broad but very important topic, that we will all be involved in at some time when supporting children or adults with profound and multiple learning difficulties (PMLD). We are likely to be involved in some form of assessment from the word 'go', with a continuing need for the assessment process at every stage of these individuals' lives. As importantly we must remember the assessment of Carers' needs.

Assessment is a process that helps us to build up a clear picture; a picture that can be shared with others. It informs us about needs, strengths and interests and gives a starting point when trying something new. Importantly it informs us how well things are going – *have we got it right?*

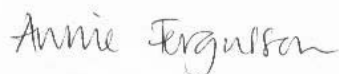
The Assessments can be carried out in a formal way (for example following set procedures) - but more often we use assessment informally through everyday 'observations' (e.g. 'how' someone is responding today, how relaxed they are, how do I know they like this drink?). It can provide information about issues like Communication, Health, education, residential and support needs for example. Assessment is as valuable for everyday situations as it is when considering major, life changes.

For people who have PMLD, the assessment process is often complicated by the very complex nature of their disability – it is never straight forward! The very smallest details need to be recognised; vital information such as the 'what' or 'who' may be crucial for an individual's quality of life and are essential to build the 'whole picture'. Building up the picture is often time consuming. For these reasons it is even more crucial that we involve the right people to ensure our assessments are accurate and complete– whatever their purpose.

Assessment can involve a multitude of people, both family members and professionals - and sometimes all of them at once! Working together this way is not always easy, and the management of coordinating a large number of professionals and contributing services calls for high organisation skills (not to mention information management), but can bring huge benefits to the person concerned. We can learn from each other's different perspectives and expertise, but most importantly what we know about the individual themselves. What is rewarding about the best forms of assessments is that we share a common focus. We all want the best outcome for the person with PMLD.

We would like to hear from you about your experiences (good or not so good) of any issues relating to 'Assessment'. Perhaps you have used some useful assessment materials that you could share with others? Do you have ideas on how we could improve on any of our assessment procedures? Can you tell us about your involvement with others in the assessment process?

I look forward to hearing from you!



Ann Fergusson (Guest Editor Winter Edition on 'Assessment')

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).

The copy deadline for the next edition is 1st November 2004.

Please send contributions to ann.fergusson@northampton.ac.uk or

paul.bramble@northampton.ac.uk or by post to the address on the previous page.

Getting a Life Not an Existence: The Benefits of Leisure to Health and Well-being for People with Profound & Multiple Learning Disabilities

By Kirsty Thomson

The benefits of exercise cannot be solely attributed to leisure behaviour. Many of us purposively exercise during our leisure time, and physical activity is required in many activities motivated by personal goals other than physical fitness. There are physical, psychological and social benefits of leisure that contribute to health and well being. People with profound and multiple disabilities have the same needs and therefore gain these benefits from leisure although this is relative due to their complex disabilities.

One of the many health inequalities facing people with severe and profound intellectual disability is reduced access to regular exercise (Common et al (in press))

The physiological benefits of regular exercise have been known for years. There are many kinds of exercise of varying intensity, duration and frequency, which produce variable effects on the body and mind. The effects of appropriate physical exercise will reduce spinal problems, improve neuropsychological functioning, increase bone mass and strength, increase muscle strength and create better connective tissue. (Cavet 1995, Leach & Bailey 1995). This improves lung capacity and in general reduces incidence of disease, therefore, in turn giving a holistic sense of wellness.

However, exercise is often extremely difficult due to physical disabilities such as being unable to weight bear and having little or no voluntary movement. Many medications used for epilepsy may contain calcium depletors, which means people with PMLD are a high-risk category for osteoporosis. (Tohill & Lavery 2001) Therefore it is important that anyone taking these medications should do regular weight-bearing exercises.

Leisure for All Project

The Leisure for All project is an expansion and development of a project carried out from 1997 – 2000 by *PAMIS* (funded by BBC Children in Need) where work began on gaining access to community leisure facilities, art galleries and museums. The overall aim of the present project is to open up everyday leisure activities to children and adults with extreme and complex disabilities. A group of people with PMLD, their families and myself are currently taking part in Taster sessions, visiting leisure venues and taking part in a variety of leisure pursuits in Scotland. During these sessions we visit and assess the facilities that are available within specific leisure pursuits. The benefits of leisure to health and well-being can be seen from this project in terms of the physiological, psychological and social.

Physiological benefits

The physiological benefits of leisure pursuits can be seen by use of adapted bikes through the *PAMIS* Leisure for All Project. This gives people with profound and multiple disabilities and their families/carers opportunities to try out activities that they may have thought would be impossible. There are two types of adapted bikes available for people to try out The Duet and The Side By Side.

The Duet bike gives the experience of being on a bike to someone who cannot sit unaided. It also gives the benefits of being out and about in the fresh air. The carer sits behind and has

control of the bike, and the person with disabilities sits in front in a wheelchair-type seat that is attached. **a)** Picture a)



The Duet bike can also be used as a wheelchair – Picture b)

b)



The Side-By-Side bike can either be used by both people pedaling - Picture c) or the pedals can remain static as a footrest for people with no voluntary movement- Picture d).

c)



d)



Cycling improves physical well - being through a number of factors. Initially by being out and about people are exposed to sunshine and fresh air, where Vitamin D is absorbed through the skin from the sun's rays. Vitamin D is needed to improve physical well being, and the physical exercise is good for the bones and muscle tone of a person with PMLD, (if they can use the pedals) and additionally it also benefits the carer's bones. Cycling is an activity the whole family can take part in and it is socially inclusive. (Tohill & Laverty 2001)

We can therefore see the need to be creative in how we adapt exercise programmes to allow access by people with PMLD. Many of these previously listed physiological benefits promote more relaxed states and other benefits occur such as a general sense of well-being.

While there is less evidence about the psychological benefits there is considerable belief that not only do these benefits exist, but also that they help promote and maintain characteristics, considerably enhance an individual's ability to function in, and contribute to, society at large.

Psychological Benefits

One of the psychological benefits which can be observed is self-confidence by being socially included unlike perhaps many of the other activities that people with PMLD take part in which are quite passive. This can bring an ability to relate to others and vice versa. Therefore, this improved interaction will also most importantly produce greater enjoyment from life. The psychological benefits of activities can be seen in activities such as Wheelchair Ice Skating - Picture e)

This activity benefits psychological well being because family and friends can skate on the ice whilst someone may physically be unable to skate, they can still do so in the comfort of their wheelchair. They can experience the enjoyment and excitement of whizzing round on the ice and taking part in the same activity as their friends. Wheelchair curling also offers the same benefits. Many families involved in the “Leisure for All” project participate in these and other leisure pursuits, interacting with their able bodied peers.

e)



Social Benefits

Last, but certainly not least, are the social benefits. Leisure activities and places can maintain and meet the unique needs of particular segments of society e.g. (the elderly, single parents, children, teenagers and people with physical disabilities) that cannot be met otherwise.

“Research indicates that people with learning disability spend their time in passive, solitary leisure pursuits.” (Cheseldine & Jeffrey, 1981)

This may be because they have a lack of control over their choices or because they rely on others to make these decisions. It may lead to them becoming passive, depressed and withdrawing if these decisions are taken from them or if they are in an unstimulating setting.

“However far the developmental disabilities of people with profound and multiple disabilities claim our attention with the therapeutic and educational needs, their lives are not, and should not be, one long intervention programme”(P.37, Hogg, 1995)

The benefits of such opportunities to the social inclusion can be observed in activities such as the Meldreth Games.

The Meldreth Games are adapted to enable people with all levels of ability to compete in a game situation. Through the games the individual is allowed to fully participate with an opponent of any ability and which can contribute to social inclusion.



Conclusion

The empirical evidence is limited on the benefits of leisure, but if properly structured and administered, it can be seen to contribute to health and well - being. In order to do this it is necessary to provide leisure opportunities for this group and allow the break down of the physical and intellectual barriers that surround most leisure pursuits.

Leisure therefore benefits health through physical exercise and improved psychological well-being, which will in turn assist integration into society. People with profound and multiple learning disabilities should be encouraged to have leisure pursuits as the same benefits are derived although relative to their complex needs. Health and leisure professionals should take the lead in encouraging people with disabilities to be physically active and ensure both that provision of information and facilities are in place for this to occur. But let’s not forget the role of day service personnel in this scenario. They too should take on board the benefits that are derived from physical activities and this should be an important component of any day service programme.

Complex needs and the barriers caused by lack of physical and intellectual access need to be addressed in future leisure provision. Only then can we hope to see a more inclusive approach

to leisure that is “Leisure for All”. This should incorporate adaptability, imagination and creativity to ensure that health and well being is enhanced.

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Further Information

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 Bury St Edmunds,
 Suffolk IP31 2AR UK
01359-251 551

Adapted Bikes
 Tweed Cycles
 17A Bridge Street
 Berwick Upon Tweed
 Northumberland
01289 331476

Adapted Bikes
 London Recumbents
 Ranger`s Yard
 Dulwich Park
 London
0208 299 6636

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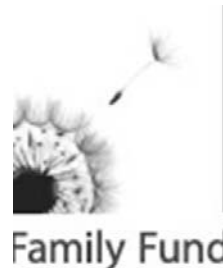
Hogg, J. (1994) Leisure and intellectual disability the perspective of ageing. *Journal of Practical Approaches to Developmental Handicap*, 18, No 1, 13-16.

Leach, M & Bailey, H. (1995) Physical activities, in Hogg & Cavet. (Eds) *Making leisure provision for people with profound and multiple disabilities*, Chapman and Hall, London.

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Making a Difference? Exploring the impact of multi-agency working on disabled children with complex health care needs, their families and the professionals who support them



This summary is taken from the Norah Fry Institute Web Page and permission to reproduce it for inclusion here was obtained and given by David Abbott (one of the research authors)

Disabled children with complex health care needs routinely require support from a wide range of professionals. Many services have been established throughout the UK that aim to implement better joint working between agencies and professionals. The Family Fund in collaboration with the Norah Fry Research Centre wanted to explore what impact multi-agency services had on the lives of this group of children, their families and the professionals that support them. Working closely with six multi-agency services the researchers found that:

- The six multi-agency services included in this research were providing effective, focused support to families in terms of managing their children's complex health care needs at home. All except one of the children included in this study were living at home, and all those who were of school age were attending a local school or nursery on a regular basis. These findings appear to indicate that multi-agency working is making a significant difference to this group of children, who in previous research, were shown to face barriers to being at home and accessing education.
- The professionals interviewed for the research were extremely positive about the process and outcomes of multi-agency working for them. They reported improvements to the quality of their working lives and to their relationships with other professionals, agencies and families.
- Two thirds of the 25 families included in this study reported that the multi-agency service had made a positive difference to their lives. There was some evidence that having a The research outlined here was the result of a study conducted by a research team from the

keyworker had a beneficial impact on families' access to services and their perception of overall quality of life. However, many families reported that social and emotional issues, as well as some practical issues around funding and equipment, were still enormously problematic.

- Many of the 18 children who took part in the study were still experiencing multiple barriers to exercising some basic human rights. These included areas of their lives such as communication, independence, friendships, relationships, leisure and recreational activities.
- Overall, the six services had worked hard to put in place structures to facilitate the process of multi-agency working. Less attention had been paid to the outcomes of multi-agency working for disabled children and their families.

Introduction

Almost thirty years of research has consistently shown that families with disabled children would prefer the many agencies that they encounter to work together more effectively. Since 1997, a strong policy emphasis on the importance of 'joined-up' working has promoted the benefits of partnerships. In response, many projects and services have been established throughout the UK that aim to implement better joint work whilst improving quality of life for this group of children and their families. There is, however, a notable lack of information about the nature of multi-agency services for children with complex health care needs. And crucially, the impact that these partnerships have on families and children.

About the study

Norah Fry Research Centre, University of Bristol, and the Family Fund. The study took

place between 2000 and 2003 and was funded by the Community Fund. The project aimed to explore the experience of multi-agency working for: • Disabled children with complex health care needs • Their families • The professionals who support them. To achieve this the research was divided into three parts: 1) An exploratory phase to determine the extent of multi-agency working for disabled children with complex health care needs in the UK. 2) Visits to 26 services to collect data about their work. 3) Case study visits involving six of the services across the UK (3 in England; 1 in Wales; 1 in Scotland; and, 1 in Northern Ireland). At each service interviews were conducted with professionals (115 in total), families (25) and children/young people (18) involved in the multi-agency service.

The six services: different types of multi-agency working in services to disabled children with complex health care needs

Each service had a different model for working with families and had approached the development and provision of its multi-agency services in a range of ways. For example, each of the services had different arrangements for defining and organising the resources needed to work together. In five of the six services, one sole agency was taking a lead role (at strategic level), in terms of funding or management. At an operational level, partnerships were fulfilled by financial contributions to care packages for individual children, and/or by staff from different agencies donating a proportion of their time to the multi-agency service. Only one of the six sites had established a truly multi-agency approach to resource sharing at both strategic and operational level. The nature of services provided to families included co-ordinating administration and/or services and support, and providing services and support. All of the six sites were acting as points of co-ordination for administration or indirect elements of care provision. In addition four of the sites were also trying to co-ordinate the actual services and support offered to families through the provision of a named person (known variously as a key worker, link worker or service co-ordinator).

There were different levels of understanding and commitment to the aims of each of the multi-agency services. Across all the sites there was little evidence of Black and minority

ethnic families accessing the multi-agency services.

The impact of multi-agency working on professionals and agencies

Working with families as part of a multi-agency team was said by professionals to be enjoyable and rewarding. They said that they had better relationships with parents and could be more effective in supporting them. Working in multi-agency services provided professionals with enhanced opportunities for personal and professional development. Staff said that they had greater insight into the work cultures of other agencies and felt enabled to look jointly at common issues. Professionals involved in joint work reported clearer and more efficient channels of communication. However, some problems remained due to different statutory frameworks, incompatible IT systems, and a lack of commitment from some agencies and individuals. Overall, professionals were almost unanimous in their belief that the multi-agency services they worked in were making a positive difference to the lives of families. However, relationships between staff and families were problematic in the areas of advocacy and scarce/limited resources.

The impact of multi-agency working on families

Multi-agency services appeared to be providing effective, focused support to families in terms of managing their children's complex health care needs at home. Nearly two-thirds of the families we interviewed reported that the multi-agency service had made a positive difference to the overall quality of their lives. However, many of the families still had difficulties with daily routines, particularly sleeping. Of those children who were of school age, all were attending a local school or nursery on a regular basis, and families expressed a high degree of satisfaction with the support and educational input their children received. Very few families had received a co-ordinated response from the multi-agency service in relation to physically adapting their homes, even where there was evidence of access to a named person or co-ordinator. Three quarters of the families we interviewed had a gross family income that was below the national average. General help from multi-agency services with financial management was often absent. The families

we interviewed all experienced major difficulties in finding and organising social activities for themselves and for their disabled children. The shortage of flexible, adequate and appropriate sitting or short breaks services was thought to be responsible for this. Most families had a very strong desire to do things together and to be perceived as a whole family. Multi-agency services did not appear to be able to respond to this and the focus of support was very much on the disabled child with complex health care needs, to the detriment of the family unit as a whole. Families reported numerous sources of emotional pressure some of which were directly related to a lack of co-ordinated and flexible support from the multi-agency services. A large proportion of families felt they had no one outside the immediate family unit to turn to for emotional support. However, nearly half of the families we spoke to felt confident that they could get this support from the multi-agency service if they so wished and where this was offered it was highly valued by families. Children with complex health care needs were not given access to emotional support, despite a need for this being apparent. Over half of the families we interviewed had access to a named person, or key worker, with a specific remit to co-ordinate services for them. Despite this, there was a distinct lack of clarity regarding the role of this person, and only six out of 25 families felt that the key worker or multi-agency service did actually co-ordinate services for them. Many of the families we interviewed were still experiencing multiple assessments and reviews. Families did not appear to have access to regular reviews of their needs or to have a clear picture of their entitlements.

The views of disabled children and young people with complex health care needs

The vast majority of children and young people we spent time with had close, but extremely dependent relationships with their parents or carers. Very few children could spend time alone with friends, or begin to develop some independence away from close family members. The children and young people we spent time with had limited opportunities for developing friendships and

relationships, although children with verbal communication were more likely to have significant friendships, underlining the importance of support for communication. It was also clear that this group of young people wanted to do the sorts of 'ordinary' things that all children do, not necessarily activities that were 'specially designed' for them. There was little evidence of effective consultation between the multi-agency services and disabled children with complex health care needs about their care and support. Even where families had access to a key worker, we did not get a strong sense that there were many primary relationships between this person and the children themselves. Some children were unaware of the identity of their key worker even when named and described.

Conclusions: Multi-agency working for disabled children with complex health care needs and their families – has it made a difference?

In a relatively short time-span, the multi-agency services, which were part of this study, had brought about significant changes for families and children in terms of better support for children's complex health care needs at home and improved access to education. What appeared to be missing, however, was a wider appreciation of what still needs to be achieved in terms of social and emotional support for families, and in terms of facilitating basic human rights for children and young people. The project team recommends that multi-agency services build upon their important work on the structure and process of multi-agency working, and develop an increased appreciation of impact and outcomes for families. Professionals are aware that multi-agency working has had a positive impact on their quality of life. Now it's time to focus attention on using the process of multi-agency working to achieve a better quality of life for disabled children with complex health care needs and their families.

Making a Difference is commissioned by the Family Fund and carried out by the Norah Fry Institute of Bristol.

November 2003

Open to all – Communication Aid Project (CAP) referral for children with SLD/PMLD

By Stephen Segal & Richard Walter

The Communication Aid Project

The Communication Aid Project (CAP) is designed to help school age pupils who have a significant difficulty in communicating with

What is CAP-official description

others, through providing assessments and communication aids to help them to access the curriculum.

When it first started it was based around the model of individual assessments of pupils by CAP teams to provide a communication assessment and recommendations. Any recommendations for communication aids would then be provided on permanent loan. This 'hit and run' approach works well for most pupils, but for pupils with profound and multiple learning difficulties this model did present some difficulties.

This was first highlighted when Becta started to receive applications for assessments for whole groups or classes from schools for pupils with profound and multiple learning difficulties rather than the individual requests they had expected.

The Scope CAP team were asked by Becta to investigate these so called bulk referrals and to formulate a plan to better meet the needs of schools with a high population of pupils with profound and multiple learning difficulties.

CAP assessments and the particular needs of pupils with profound and multiple learning difficulties

What are the difficulties in CAP for PMLD

There are sometimes different challenges for CAP referrals for pupils with profound and multiple learning difficulties that arise from their particular communication needs.

Some of these are:

- *the communication of the whole group is strongly interrelated*
- so that it can be more effective to assess the whole group rather than individuals. This also highlights the importance of a whole school **Total Communication** policy.
- *the communication of the whole group relies to a greater extent on getting the environment right for communication which*

requires major commitment and support from all classroom staff

- so a greater emphasis on the training of all classroom staff in the consistent use of AAC techniques, in communication and sensory interaction is essential.

- *the communicative development of the pupils is closely linked with pupils' physical and sensory experience*

- so that it can be difficult to separate out 'communication' from other activities and the development of communication skills is not an obviously progression but is more heavily related to enrichment of experiences.

- *the cost of the individual's communication equipment can be much less than the cost of the actual assessment*

-so it is often more efficient to assess a group rather than an individual.

A further important difference might be in the actual technical operation of the communication aids.

For example a BIGmack (which might be used to support the communication of pupils with profound and multiple learning difficulties) is much easier to setup and operate than a Dynavox.

But using a BIGmack practically and meaningfully in class with pupils with profound and multiple learning difficulties can actually be more complex than using a Dynavox to support the communication of a more able individual pupil.

To use a simple communication aid successfully may require a more imaginative approach than using a more complex one!

What is the scope CAP teams PMLD plan?

Part of the Scope CAP team is based at Scope's Meldreth Manor School where we have a great deal of experience developing communication with pupils who have profound and multiple learning difficulties.

We thought that the communicative needs of these pupils would be better served by an assessment model that included a greater concentration on setting up and developing a whole class or school communicative environment with a much greater emphasis on staff training in AAC and interactive techniques.

This might include

- the use of intensive interaction
- the use of rhythm (call and response/beat that)
- the development of sensory experiences and communication (so promoting simple choices)
- the use of objects cues and objects of reference
- the use of simple, repeated language activities
- the use of simple single channel Vocas to support simple interactions (in stories, greetings, songs etc).
- the use and development of switching skills for controlling devices and using cause and effect software

However we also felt that it was vitally important to keep the rigour and quality associated with CAP assessments. We did not want simply a watered down CAP assessment for groups of pupils with profound and multiple learning difficulties.

The importance of the CAP project in providing individual pupils with communication support is clear, there are sometimes additional issues in providing support for pupils with profound and multiple learning difficulties. The additional emphasis of CAP assessments for pupils with profound and multiple learning difficulties means that a CAP assessment might be less to do with providing individual pupils with their own communication aids and more about providing aids, activities and support for the communication of a whole class or classes in a school.

The final and very important part of this plan is to

- *Develop partnership between the schools, the LEAs, the health authority and the CAP assessment team*
- by supporting the development of the skills of local teams in the schools and LEAs we hope to enable a sustainable infrastructure to be created after the CAP funding finishes.

How does the plan work?

Outline how the plan works with the schools.

We have identified a small number of schools to work alongside either through personal contact or through strategic alliances with the LEA. They all have classes of pupils with profound and multiple

learning difficulties and have staff who are committed to the use of communication aids. The basis of our collaboration is around a small number of children who have been referred as a group to CAP.

Our partners in the initial stages of this pilot work are:

- Springhead School, North Yorkshire
- Wyvern School, Dorset
- Heritage House School, Buckinghamshire
- Watergate School, Lewisham
- Fairfields School and Greenfields School, Northamptonshire, working with Redway School, Milton Keynes

Many of these schools have experience in working on the assessment of children with PMLD. Where necessary, we will support the school to carry out their own communication assessments by

- providing training in communication techniques with pupils with profound and multiple learning difficulties.
- demonstrating and lending them a range of communication aids for use and assessment with the students.
- supporting staff evaluating the use of the communication aids by telephone, email and video links

Over a term the schools will then complete CAP assessments of their own pupils with the communication aids provided. Modifications to the communication aids provided can be also be made in liaison with the Scope CAP centre.

In this way schools will develop their own expertise in the use of communication aids and they will identify their own training needs. We hope that these skills will cascade into schools throughout LEAs so that when CAP finally finishes its legacy is not simply that a number of pupils have been assessed and provided with communication aids but also the staff skills to develop communication in pupils with profound and multiple learning difficulties will also have been enhanced.

We feel that this is very important pilot work. It may inform on the future handling of CAP referrals for groups of children with PMLD. We will keep you informed as we move forward.

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Keyworkers are an essential part of a quality service for families. So why do most families not have one? Is the “Team around the Child” part of the solution?

A personal view, Peter Limbrick, chair of the Handsel Trust and independent consultant in Interconnections

It is generally acknowledged now that a multi-agency keyworker should be offered to each family who has a baby or young child with complex needs. This has been documented over three decades in research, surveys, reports and guidance and yet still the majority of families do not have one. It is interesting to speculate why keyworking has not been widely adopted by service providers in spite of the obvious need. In my view the reasons include overloading practitioners who agree to add keyworking to their main professional role, inappropriate expectations of what keyworkers can achieve and a general failure to treat keyworking seriously within organisational systems. The Team around the Child approach is offered as a remedy to some of the problems.

Overloading shared-role keyworkers

The great majority of keyworking services have relied on existing practitioners agreeing to become keyworkers for a number of families and then dividing their time between the main professional role and keyworking tasks. This is because funds have not been available to provide new teams of single-role keyworkers. The typical situation is that these practitioners are already busy enough with their present case-loads but are willing to ‘go the extra mile’ because of their acute awareness of the needs of the families they support.

Logically, when new work is added to a busy practitioner’s work-load, other work should be taken off them so that their job remains do-able. In my experience shared-role keyworkers are not always given this consideration. If the practitioner has one manager for the keyworking role and another for the main role, tensions and disagreements can arise about how much time is allocated to each role. If the practitioner is relieved of some duties to make room for keyworking, it can leave the line manager with no option but to share that work out amongst other members of the team. Assuming that these people were already busy, they will become over-loaded with this additional work. This in turn will reduce their capacity to take on shared-role keyworking.

It seems inescapable that additional resources are needed if families are to be offered either single-role keyworkers or shared-role keyworkers. A test of this need for additional resources is for service providers to project ahead three, five and ten years to anticipate the probable demands as keyworking is offered to an increasing number of families in their locality who require it. Services which expand their shared-role keyworking service to the point where they have no more practitioners to call on for the shared role will have a choice of rejecting new families or seeking funding for more practitioners.

Inappropriate expectations

There can be pressure on keyworkers to undertake tasks which go beyond their training, their status and their available time. The pressure might come from the family or from the keyworker’s employer or it might come from the keyworker’s own commitment to doing as much as possible for the family. Four examples are:

(i) Keyworkers trying to be advocates. This role can require keyworkers to attempt to exert an influence over service provision going well beyond their status and the power invested in them. Advocacy can compromise a shared-role keyworker’s relationship with his or her employer. A

distinction must be made between the appropriate keyworking role of helping families get what they need (so they don't have to shout and battle for everything) and the inappropriate role of supporting the family in complaints or other formal approaches to service providers. When families require formal advocacy they should be linked to an appropriate advocacy service.

(ii) Keyworkers trying to co-ordinate services. Keyworkers cannot create strategic multi-agency collaboration, single-door referral systems, joint assessments or integrated pathways. This is the task of senior management from health, education, social services and the independent sector. When an effective co-ordinated system is in place, then keyworkers have a favourable environment in which to keep everyone linked together for the family. When services are fragmented and piecemeal the keyworker is very limited in what he or she can achieve. Keyworking should be viewed as an important element of service co-ordination but not as service co-ordination itself.

(iii) Keyworkers giving advice. Parents of children with complex needs will have to make many decisions which will impact on the well-being and survival of the whole family and on the well-being and perhaps the survival of the child. Keyworkers are not competent to give advice. Their role is to ensure the parents have good information about the issue and perhaps to support them as they think it all through.

(iv) Keyworkers giving significant emotional support. Many parents need emotional support from time to time. This might be a priority for new parents. Provision of emotional support by keyworkers varies between just being an occasional listening ear to being the one person to whom family members off-load their experiences, feelings and emotions on a regular basis. Having someone to talk to is a therapeutic activity which can help parents adapt to the most challenging situations and help resolve any negative emotions which stop them moving on. This can make unrealistic demands on a keyworker's time. Most shared-role keyworkers, like most practitioners anyway,

do have time to be an occasional listening ear but should only offer more than this if they are sure they have the time and skills required. Families who require more emotional support should be referred to a relevant agency.

Lack of proper systems

Keyworking has mostly slipped informally into service provision without job descriptions, training, protocols, standards, career structure, management, support systems, monitoring, clerical support or proper funding. Keyworking projects, like the families they are trying to help, are very vulnerable. They can collapse when a particular enthusiastic practitioner or manager moves on, when practitioners opt not to assume the shared-role or when temporary funding dries up.

The Team around the Child (TAC) approach

This provides each family with an individualised and evolving team (of just three or four or five) multi-agency practitioners who meet every half-term or so to review the child's progress, to discuss pertinent issues and to up-date the family support plan including the child's development and learning goals. Each TAC includes parent or parents and has its own Team Leader (with a shared-role). The Team Leader functions as the family's multi-agency keyworker. In a real sense, the TAC approach provides an effective response to the need for keyworkers. It keeps the role within manageable parameters until such a time as funds become available to develop keyworking further. The basic role consists of -

- developing a helping relationship with the family and being a listening ear
- keeping a list of all agencies, services and practitioners involved
- ensuring the family has all the information they require
- ensuring the family has access to all relevant services, resources and benefits
- leading TAC meetings
- ensuring each meeting results in a multi-agency support plan

- ensuring the plan is distributed to other agencies, services and practitioners
- supporting the family as necessary through all parts of this process

This can be seen as minimal approach to multi-agency keyworking. But we have to acknowledge that children and families are all unique in their needs and that TAC Team Leaders come from a variety of professional backgrounds and working conditions. In response to these varying conditions there might be pressure from the family, from the keyworking service or from the TAC Leader him or herself to expand the role. This should only happen if the TAC Leader is competent to perform the new role, has sufficient time for the additional tasks and has all necessary resources and support.

The design of the TAC Leader's role overcomes common obstacles and negative perceptions around keyworking. The role is very clearly defined and delimited, it falls to existing practitioners (from local statutory or voluntary services) and the TAC Leader is part of the supportive team rather than being an additional person grafted on to it. Formal advocacy is excluded from the role as is extensive emotional support. TAC Leaders operate within a supportive and co-ordinated matrix and are trained, resourced, supported, monitored and evaluated.

TAC Leaders must carry some authority, as must other keyworkers, if they are to be effective intermediaries between families and their local services. The TAC approach empowers TAC Leaders in the following ways.

(i) In dealings with the agencies and services around a family, the TAC Leader is a spokesperson for the TAC and does not just speak for himself or herself. As the TAC by definition comprises the handful of practitioners who are most closely involved with the child and family and who collectively hold the most rounded and detailed information about them, the Team collectively carries authority and status which equals or surpasses that held by anyone else involved with the family. This authority is invested in the TAC Leader.

(ii) Each TAC Leader operates within a system which is established by multi-agency agreement with principles and protocols about how TAC Leaders and local services will collaborate with each other in pursuit of effective support for children and families.

(iii) Within this system there is training and support for TAC Leaders to enable them to be effective communicators and negotiators.

(iv) The TAC system and the TAC Leaders within it are monitored so that lessons can be learned when TAC Leaders find themselves unsuccessful in representing the needs of children and families to other services and agencies.

(v) Within the TAC system there will be a senior manager or a management group overseeing the system and providing support to TAC Leaders. This person or group can support any TAC Leader who encounters difficult situations or seemingly unmoveable obstacles.

Services for children with disabilities and their families have never been adequately funded. I expect that this will not always be so and that funds will be made available to local councils, health services and voluntary agencies to enable them to provide families with a choice of single-role keyworkers or shared-role keyworkers. Meanwhile, the TAC approach can represent the best attempt we can make to give families multi-agency keyworkers who are empowered to support families within a system which is well organised, co-ordinated and accountable.

Peter is happy to enter discussion.
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Peter Limbrick is author of 'The Team around the Child – multi-agency service co-ordination for children with complex needs and their families' and 'An Integrated Pathway for Assessment and Support – for children with complex needs and their families'. Both are published by Interconnections and available by mail order from Interconnections, 9 Pitt Avenue, Worcester, WR4 0PL. Tel/fax: 01905 23255

Sleep Scotland *helps the Sleepless!*

Emma Vinnie and Jane Ansell

Imagine the disturbed nights for a young baby going on for years. Imagine your children growing up but still taking hours to settle, and getting up many times during the night. This was the situation that led Jane Ansell to set up 'Sleep Scotland', a charity for **families of children with special needs and severe sleep problems.**

The Sleep Project

In 1998 **Sleep Scotland** was funded for one year by the National Lottery Charities Board (NLCB) to investigate whether there was a need for a service dedicated to helping the families of children with special needs and severe sleep problems. At the end of that year there was sufficient evidence that these families needed help, and in 1999 the NLCB funded a three year project:

- To **train** and **support** Sleep Counsellors throughout Scotland
- To **establish** Sleep Clinics throughout Scotland
- To **support** parents through new and existing support groups throughout Scotland
- To establish a **telephone helpline** for parents and professionals
- To **raise** the **profile** of sleep problems

What is Sleep Counselling

Sleep counselling is to help families teach their children to sleep. It is used where children have difficulties learning to go to bed, to settle and to stay in bed throughout the night. Sleep Counselling is based on specifically adapted behavioural and cognitive techniques. Children who have special needs often have long-term sleep difficulties which can devastate whole families. Sleep counselling improves the quality of life for the children, their siblings and their parents and helps families to face the many other challenges they face.

Why is Sleep Counselling needed?

Severe sleep disorders.....

- are more common in children with special needs
- can go on for years

- are a major cause of stress in the family
- reduce quality of parental care for all the family members
- adversely effect the development of siblings
- are often cited as reasons for family break-up
- are often cited as reasons for dual-parent unemployment
- can cause mental health problems for all family members
- often cause families to decide on residential care for their child

But....

Research shows that if parents can address the sleep problems, improvements can follow in the quality of care, control and confidence by the parents and the physical and mental health of the family

Why do children with special needs have sleep problems?

- There may be a physical basis for sleep problems e.g. Cerebral Palsy, (turning, positioning, reflux), Eczema (itch/scratch cycle), Epilepsy (seizures)
- Communication disorders e.g. autism are often accompanied by rituals inimical to good bedtime routine
- Children may be hyperactive e.g. AD(H)D
- They may have poor memory skills or cognitive skills and have never learnt how to go to sleep in their own bed

- Prolonged hospitalisation in infancy
- Parents may never have established a good bedtime routine because the burden of caring is too tiring
- Parents may unwittingly disrupt a child's sleep pattern by being over-protective or over-stimulating
- Medication may interfere with natural sleep cycles
- Over-tired children are often hyper-active and have attentional deficits. They are often very irritable, over-emotional and difficult to manage. In children with special needs these symptoms may be ascribed to their condition/ and tolerated rather than addressed
- There may be psychological factors underlying sleep problems such as nightmares
- There may be respiratory problems

Apart from the last two causes, there is likely to be an element of learned behaviour in all these sleep problems. This can be changed.

The Solution

Sleep problems can be effectively managed using specially adapted behavioural and cognitive techniques.

This reduces stress levels for the parents which in turn leads to improved health and quality of care for the whole family.

Parents and carers can look after their children better, and make the best decisions about care for their special needs children.

Sleep Scotland has designed and delivers an evidence-based intervention which an independent evaluation has shown to be effective. The effects on families go wider than resolving sleep problems, with parents able to tackle other behavioural difficulties, and to look at other ways of improving their family life eg taking holidays together, returning to work, and developing a social life.

The basic criteria for inclusion in a programme:

- Severity of night settling/waking sleep problems; they must present

on a minimum of four nights per week and comprise 60 minutes wakefulness either prior to sleep onset or during the night.

- Chronicity of sleep problems; they must have persisted for at least the preceding 6 months.

When a family express an interest in attending a Sleep Clinic they will have completed a Personal Information Form giving brief background details about their child's sleep problem. By the time they have completed the initial interview with a General Health Questionnaire to assess stress levels, and have completed the Parental Interview Schedule, the Counsellors are able to build up a picture of the child and his or her family prior to making decisions about a programme.

Families are expected to have an average of 8 – 10 meetings with the sleep counsellors. At least one home visit is made to each family. At the first appointment the counsellors take a detailed sleep history to document the evolution and current sleep problem, as it is perceived by the parents. Parents are given sleep diaries and asked to record the child's sleep patterns for two weeks. At the second and subsequent appointments the counsellors work with the parents to set targets for improvement and to devise a detailed programme of behavioural and cognitive interventions to change the child's sleeping patterns. New families receive a follow up phone call within the first week of their programme to check their progress and to encourage them. The sleep counsellors then work with the family to support the implementation of the sleep programme beginning with night settling, then focussing on night waking, and lastly on early morning rising. The Sleep Counsellor and family will review the treatment programme on fortnightly basis, interspersed with telephone calls required.

The programme ends by mutual consent either when parents meet their targets or the counsellors feel that they are no longer helping the family to make progress. A formal system for assessing success is implanted for each family by the counsellors at the beginning and end of the programme.

Our Sleep Counsellors are from a variety of backgrounds i.e. health, education, social work and the voluntary sector. They have

experience in working with the families of children with special needs and therefore bring experience and skills with them. They are recruited with the support of their employers to further assist families of children with special needs.

The following case study gives some insight into parental difficulties and the effects of the Sleep Programme on one family. However, it is important to note that one of the crucial elements of the programme is the Sleep Counsellors support – the wonder of someone being there to listen to you and guide you.

Case Study

Brian was the middle of three children and had complex learning difficulties with autistic tendencies. He was non-verbal though now aged 6 and was learning to communicate through screaming! The family was suffering from chronic fatigue and his elder brother from stress. Brian's major problem was settling to sleep and remaining asleep. In order to prevent his screaming his waking was inadvertently rewarded by his parents with juice, massage, and his parent's company. In their Sleep Clinic the parents and Sleep Counsellors together drew up a Sleep Treatment Programme and agreed that:

- The parents would check to ensure Brian was safe and warm;
- They would not respond immediately to his cries and not remain in the room;
- No juice, massage or parental attention would be given.

In addition they would also consider delaying Brian's bath/bedtime routine until slightly later; take him out for a nightly walk to tire him out; and cover or remove the toys in his bedroom at night.

This advice worked well and Brian responded by showing an improved sleep pattern during the night, and less screaming during the day as well. Gradually other changes to the meal

and bedtime-time routine were instigated as the parents gained in confidence and became more relaxed. The improvements affected the 7 year old elder brother too, and at the end of the programme he wrote, "My mum says you might be interested in knowing how I feel now that Brian is sleeping better. I feel much better and don't feel as angry with Brian anymore."

Achievements

Over the past three years Sleep Scotland has

- **Trained 174 Sleep Counsellors** in behavioural and cognitive techniques, specifically tailored to help the parents and carers of children with special needs
- **Established 80 Sleep Clinics** from Orkney to Dumfries and Stornoway to Aberdeen. 217 families have attended these clinics to improve their child's sleep patterns.
- Provided telephone support to 1555 families and 1454 professionals

Figures correct as at March 2004

Presently

Sleep Scotland deliver Sleep Counselling throughout Scotland. It is now funded mainly through Local Authorities, NHS Trusts and the Scottish Executive. Our new developments are: Local Co-ordinators in order to decentralise the service; and Sleep Counselling via video-link. We are always interested to hear from anywhere in the UK about needs, gaps or developments in Sleep Counselling services.

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sleepscotland@btinternet.com

Editors note

The following project is reproduced here with the consent of its authors who invite comments (contact information in article).

The full article is 19 pages hence only a part is included here. The first section discussing the project is here in its entirety, however only 5 pages of the tool itself are included to give the reader a flavour. The other sections include dental, vision, hearing, list of conditions, smoking exercises, toileting, female/male specific and views about visiting the doctor.

Health Matters

by Pat Bushell, Liz Bridgma, Lucinda Harding, Daniel Marsden

Health Facilitation in Balfour Enhanced Care Unit (ECU)

This document describes the proposed pilot process of Health Action Planning for use by Enhanced Care Unit service users and staff. This includes how the process is planned, and reason for each step, and the expected results.

It is intended that the Enhanced Care Unit (ECU) with support from health services will provide an *enhanced health service* for those that require it

Background



Enhanced Care Service at Balfour work with people who have severe and profound learning disabilities, along with additional disabilities such as sensory impairments and physical disabilities. In some cases staff also work with individuals who have complex physical health issues, such as peg feeding and physiotherapy programmes.

This client group receive an enhanced social care service from the local authority, and when appropriate the Learning Disability Health Team have provided either one to one support for service users or have run groups with clients and staff at the Unit. While this has provided effective short term support to all involved with the Unit, the advent of Valuing People (2001) offers a new opportunity to establish a three way partnership between Enhanced Care, Learning Disability health professionals, and Primary Care services.

Health Facilitation in Enhanced Care Unit

Health Facilitation is about making sure people with learning disabilities receive an equal health care to everyone else. But some people's needs cause them not to be able to explain their aches and pains, putting them at a disadvantage. The Health Facilitator will ensure that each person has or are offered a Health Action Plan. This document will contain up to date health information on that individual, and is aimed at preventing ill health and the early diagnosis and treatment of illness.

The Government (2002) split up Health Facilitation into two main jobs:-

<i>Health Facilitation levels</i>	<i>Definition</i>	<i>Enhanced Care Unit</i>
<p>Level 1</p> 	<p>Service Development – creating partnerships, systems to reduce inequalities</p>	<p>Project prompted by Liz Nicholas & Jo Poynter. Designed by Pat Bushell, Liz Bridgman & Daniel Marsden</p>
<p>Level 2</p> 	<p>One to one work with clients – Organise and ensure accuracy of Health Action plan with support from health professionals</p>	<p>Carers – parent, residential, ECU key-workers, Care Managers and others who attend Health Action Plan meeting.</p>

The role of the parent or residential carer is not to be underestimated in this process; they will have taken the health facilitator role unknowingly for many years, in some cases for the whole of the service users life. When the service user goes home in the evening it is these individuals who become their health facilitators again. Service users direct carers will be sent an invite for this meeting, which will include a Pre-Screening Checklist. This will give invaluable information regarding the service users health issues and support required from ECU staff and Primary Care.

Health Action Planning: the process

Initially five service users have identified and will be contacted by telephone to advise that this pilot project is taking place and to offer them a place on it. Five service users have been identified by ECU. Invitation letters and the Pre-Meeting Checklist (adapted from work by Jayne Davis – Hereford Community Team) will be posted out; a letter will also be sent to the service users General Practitioner, explaining the project, and what support may be required following the meeting. ECU key-workers may wish to complete a Checklist, possibly in collaboration with residential or parent carer. An agreeable time and place must be confirmed with all invited.

The meeting will provide an opportunity for health concerns for be discussed, for further information to be gathered and to share responsibilities for developing the Health Action Plan. It is expected that an effective Health Action Plan will require support and further information from health professionals at the service users doctors’



surgery. It is possible that other health professional's advice may need to be sought.

The initial meeting and subsequent visits to the GP's for assessment will provide a baseline for future reviews, where unless circumstances change significantly, health will be incorporated into the Service Review system.



However, this is not to say that the Health Action Plan is finished. Like a person centred plan, the document is intended to grow with the individual, and will include space to report on health concerns, advice sought from health professionals and test results. New information can then be shared as appropriate with others who may be working with the service user.

Results

It is believed that this process will have a number of positive results for the Enhanced Care Unit, its staff and service users. This process:-

- 1) Will highlight areas of service users' health that all carers need to be aware of. This may include mobility within ECU, or the differences in communication styles between home and ECU.
- 2) Will provide a baseline of an individual's health, which can be reviewed as often as carers and the service user wishes.
- 3) Will calm anxieties of carers, by providing answers to simple questions, signposting to other professionals, and advocating for service users via letters to primary care professionals.
- 4) Will support ECU staff to identify training needs for working with service users' health issues.
- 5) Will develop relationships with primary care services, ensuring that part of the Health Action Plan is complete prior to any future general health assessment offered by GPs.



Evaluation

This work can be evaluated in a number of ways. Firstly, care staff will be asked to complete an evaluative questionnaire, which will refer to staffs' understanding of the meeting, the reason for it and their feelings toward it. This will also consider how this process could be improved.

Auditing the ECU Health Action Plans would provide information as to how the process is working; it would also highlight successful interventions by health facilitators, which could then be shared with other services.

As this is the initial area for piloting Health Action Plans it is expected that staff and service users will be flag bearers for this process. As such it is hoped they will be able to educate people with



learning disabilities, care staff, and primary care staff on the process and how it can be improved.

It is expected that this process will also offer new –and possibly more specific– definitions as to what Health Facilitation means in Medway, and how that fits into person centred planning. One thing that is clear, the initial health action plan will require further partnership building with GP surgery’s, which will spread the word of Health Action Planning.

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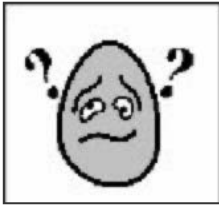
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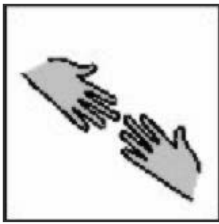
Pre - Health Meeting Questionnaire



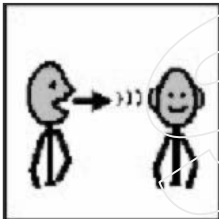
Please fill in this form and bring it with you to your appointment.



If you can't answer some questions, don't worry, just leave them blank.



You may want a carer or friend to help you.



It will give you an idea about what we will be asking you.



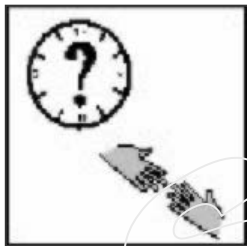
Do you have any problems taking your medicine or tablets?

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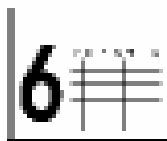


Which doctor gives you your medicine or tablets?

.....



When did you last see them to talk about your medicine or tablets?



6 months



1 year



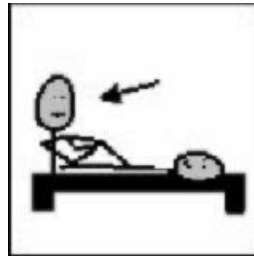
longer



Do you get help from any of these people?



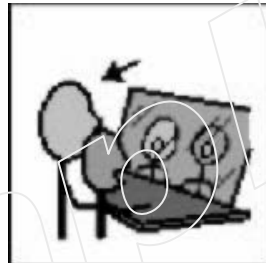
Community nurse



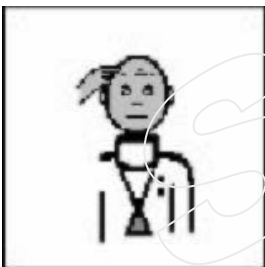
Physiotherapist



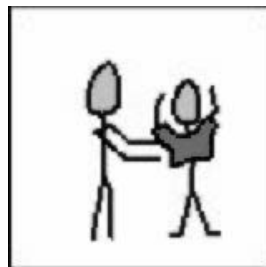
Care manager



Speech therapist



Psychologist



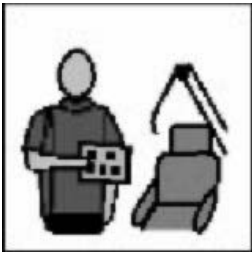
Occupational Therapist



Psychiatrist



Anyone else



Who is your dentist?

.....



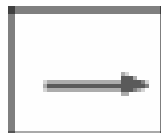
When did you last go to your dentist?



6 months

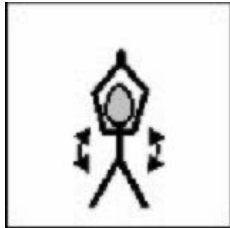


1 year

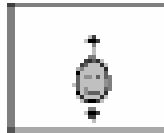


longer

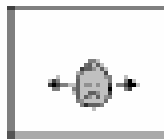
Sample



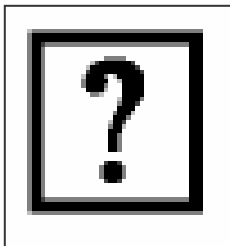
Do you do any exercise?



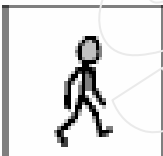
yes



no



What exercise do you do?



Walking



running



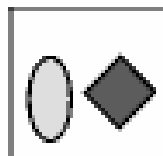
swimming



horse riding



trampolining



something else

EDITORS NOTE

I WOULD LIKE TO THANK PETER LIMBRICK FOR ALLOWING US TO INCLUDE IN OUR EDITION HIS *ELECTRONIC BULLETIN* BELOW, WHICH HE PRODUCES ON A MONTHLY BASIS. PETER HAS KINDLY ALLOWED US TO REPRODUCE IT HERE, BUT YOU MAY LIKE TO ENTER THE EMAIL ADDRESS INTO YOUR COMPUTER AND CONTACT HIM YOURSELF TO RECEIVE MONTHLY UPDATES. THIS IS THE JULY 2004 EDITION.

ELECTRONIC BULLETIN ABOUT CHILDREN WITH DISABILITIES / SEN
Peter Limbrick

CONTENTS

1. News from Central Government
2. Is a diagnosis important?
3. Handsel Trust Conference 'Planning Family Support'
4. 1 Voice - Communicating Together
5. Conference: Heading for Inclusion
6. Parents have needs too!
7. Inclusion Now - The Magazine of the Inclusion Movement in the UK
8. Seminar in Newcastle: The Team around the Child (TAC)
9. SIGNalong Update Newsletter
10. UK Health Care and Learning Disability Network

If you have time, please forward to interested colleagues

Do you have news, information, questions or events for these electronic bulletins?

They go initially to 2300+ people in all parts of the UK and Ireland and then into many other local networks. This is a free service.

Please send your material in an e-mail message and ready for use
The bulletin does not use attachments

Please let me know if you wish to change, add or remove a name from my e-mail distribution list.

With very best wishes

Peter Limbrick
Independent consultant in Interconnections
[& Chair of the Handsel Trust
9 Pitt Avenue, Worcester, WR4 0PL.
Tel/fax: 01905 23255
E-mail: p.limbrick@virgin.net

1. News from Central Government

Distributed in an e-mail bulletin by Kevin Woods, SEN & Disability Division, DfES

(i) *Every Child Matters*: Inspecting services for children and young people

On May 11 Ofsted on behalf of the inspection agencies launched a discussion paper on an integrated approach to the inspection of children's services. These proposals come from a steering group of commissions and inspectorates set up to take forward work on inspection in the light of '*Every child matters*'. Disabled children get a particular mention in two areas: they will be targeted to ensure council's analysis of the views of service users include disabled

children; and they will be covered in details under the proposed Joint Area Reviews. Further details are available from

<http://www.ofsted.gov.uk/publications/index.cfm?fuseaction=pubs.summary&id=3637>

(ii). Government's Annual Report on *Valuing People* - Learning Disability White Paper

The Department of Health has published the second annual government report on the implementation of White Paper *Valuing People* which includes a chapter on disabled children. The report responds to the Learning Disability Task Force report entitled 'Rights, Independence, choice and inclusion'. For further information from

http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4081016&chk=Hu41uP

(iii). DfES Director General's visit to Contact a Family

DfES Director General of Children and Families Directorate, Tom Jeffery, went to Contact a Family's (CaF) Head Office on 5 May. Tom is the most senior Government official responsible for delivering the Green Paper Every Child Matters. He met Francine Bates, the Chief Executive and visited the organisation's national freephone helpline for parents of disabled children, which is funded by an annual £500k grant from DfES. In his two hour visit Tom also met local parents and Barbara Reissner from the local Hoxton Sure Start who, with the support of CaF, is employed to support families with disabled children in the immediate vicinity.

Tom Jeffery said "I was delighted to be able to visit Contact a Family and see their telephone helpline in operation. The helpline is a great success enabling thousands of parents to receive quick advice and help. It was a great pleasure and very instructive to meet with some parents of disabled children and hear their views about the services they would like to receive. They were forceful and eloquent in their aspiration for much better, more accessible support. Not surprisingly they wanted to receive co-ordinated, high quality child centred services which promote social inclusion and allow their families to live ordinary lives as far as possible. I was particularly impressed with the support being offered by the local Sure Start project. We want similar multi-agency provision of services provided elsewhere including through Children's Trusts, the new Sure Start Children's Centres and full service extended schools. The particular needs of disabled children and their families should be central to the implementation of Every Child Matters and the forthcoming Children's National Service Framework. To me an essential test of whether we succeed in our vision for children's services is whether disabled children and their families see an improvement in the support services they receive."

(iv). Commission for Equality and Human rights

The Government has published a White Paper which proposes the creation of a new Commission for Equality and Human Rights. This will bring together the three existing commissions including the Disability Rights Commission. The White Paper can be found at t.gov.uk/equality/project/cehr_white_paper.pdf

(v). National Early Intervention Centre

DfES are funding Mencap to carry out a feasibility study on the benefits of the setting up of a National Early Learning Centre on children with SEN or disabilities. The centre could: Give information to parents and practitioners about early intervention; Carry out or commission research into early intervention; Publish key research messages in appropriate formats; Develop courses for parents and practitioners. Further information from <http://www.earlyintervention.org.uk>. The website includes a parent survey.

(vi). Parenting fund

In May, Margaret Hodge, Minister for Children, Young People and Families, launched the £15m Parenting Fund, which will be distributed entirely through the voluntary sector. The Fund incorporates a major grants programme, of about £9.5 million; and a local grants programme of about £6 million. The major grants, up to a maximum of £350,000, are aimed at supporting larger organisations. The local grants, up to a maximum of £100,000, are restricted to 18 geographical areas. Both will focus on families with issues that are currently less well-served, which include "Families living with disability." For further information including application forms visit <http://www.parentingfund.org/>

(vii). An evaluation of TransPlan

The TransPlan CD-Rom is a guide to the process of transitional planning as it impacts on young people with special educational needs, aimed at young people, parents/carers and services and agencies involved. TransPlan CD was developed by a regional multi-agency group of different professionals in the North East facilitated through the North East SEN Regional Partnership between September 2001 and September 2002. DfES have funded an evaluation for TransPlan. This said "TransPlan was seen to be an excellent, comprehensive, much needed and useful resource." Details of report available at http://www.connexions.gov.uk/partnerships/publications/uploads/cp/TransPlanEval_Report.doc. There are still a few copies of the CD-Rom available at dfes@prolog.uk.com quoting TRANSPLAN1 or calling 0845 6022260.

(viii). CDC Publication - The Dignity of Risk

Funded by DfES, this Council for Disabled Children, handbook has been produced to promote the inclusion of disabled children in community life. The changing complexity of disability means that many children with additional needs are seen as 'too disabled' for services. The book concentrates on the background to issues including invasive care, moving and handling and physical intervention and provides practical forms and protocols to be adopted by all family support services. It will be particularly useful for providers of short-break services, in-home care such as sitting services, befriending schemes, play-schemes, weekend leisure services and after-school clubs. However, much of the policy and guidance is transferable to other settings and it will be of interest to schools and residential settings. To obtain copies see Web: http://www.ncb.org.uk/resources/res_detail.asp?id=549

(ix). Disabled Children in Residential Placements

In *Valuing People* the Government gave a commitment to find out more about the the numbers, circumstances and outcomes of disabled children in residential placements provided by Social Services, Education and Health in England. The DfES has published a report which contains this information and makes recommendations to improve the support, safety and welfare of disabled children living away from home. The report can be downloaded from :<http://www.teachermet.gov.uk/docbank/index.cfm?id=6462>

(x). DH/DRC Framework for Partnership Action on Disability

Health Secretary John Reid and Chair of the Disability Rights Commission, Bert Massie have announced a joint Framework for Partnership Action on Disability to help deliver improvements for disabled people in health and social care settings. Although mainly concentrated on adults, some of the proposals around access to NHS facilities and training of staff will help improve services for disabled children. Further details from http://www.dh.gov.uk/PublicationsAndStatistics/PressReleases/PressReleasesNotices/fs/en?CONTENT_ID=4083525&chk=fL3%2BWz

(xi). CaF Support Pack for Health Professionals

Funded by Department of Health, Contact a Family have produced a support pack *Working with families affected by a disability or health condition* to provide health professionals with practical suggestions on how best to communicate information and offer appropriate support to parents at significant times from pregnancy to pre-school. The support pack is primarily intended for ultra-sonographers, obstetricians, midwives, neonatal nurses, paediatricians, health visitors and counsellors. The pack can be downloaded from <http://www.cafamily.org.uk/reports.html>

(xii). DH Funding for National Autistic Society

Health Minister Stephen Ladyman, has announced a new funding boost of £156,000 for the National Autistic Society's 'Social Skills-Young People with Asperger Syndrome' project. This provides a network of social groups for young adults with Asperger Syndrome and will enable the development of self-advocacy in a safe and knowledgeable setting. Further details from [:http://www.dh.gov.uk/PublicationsAndStatistics/PressReleases/PressReleasesNotices/fs/en?CONTENT_ID=4082311&chk=QKz%2BzB](http://www.dh.gov.uk/PublicationsAndStatistics/PressReleases/PressReleasesNotices/fs/en?CONTENT_ID=4082311&chk=QKz%2BzB)

2. Is a diagnosis important?

From Maggie Ponder and Helen Statham

We are currently undertaking research with families where two or more males have a learning difficulty or disability with no known cause. The families are taking part in molecular studies which may possibly give them a genetic diagnosis. We are exploring with a range of family members what they perceive will be the advantages and disadvantages of having this information. We are also interested to know the opinions of people working with families where children have disabilities/special needs as to whether or not a named diagnosis is useful. We would be grateful if you would fill in this short questionnaire. If you have colleagues who do not receive this electronic bulletin who you think will be interested in this study, please forward this questionnaire to them.

It's probably easiest if you paste the questionnaire below into a new word document and complete it there. If you have difficulty in accessing or downloading, please contact us at families@hermes.cam.ac.uk and we will send you a version as an attachment or, if you prefer, a printed version.

You can email your responses to us at families@hermes.cam.ac.uk or you can post a reply to: Maggie Ponder and Helen Statham, Centre for Family Research, Free School Lane, University of Cambridge, CB2 3RF. Everything you say will be confidential.

Questionnaire

1. When a child has a disability the cause can be known eg a chromosomal problem, a genetic disorder, or birth injury. Very often, however, there is no known cause. *In your opinion* what are the advantages AND disadvantages of a definite and named diagnosis for:

- a) you as a professional/voluntary worker
- b) the services that the child can access
- c) the child's family

2. What is the nature of your interest in support for families with children with disabilities/special needs? Please tick all that apply

Professional if so what do you do?

Voluntary if so, what do you do?

Personal if so what is your relationship to an affected child/children

3. **Where do you live/work?** England Scotland Wales N. Ireland Eire

4. **Are you** Male Female

5. **How old are you?** Under 25 26 – 35 36 – 45 46 – 55 56 – 65 over 66

Thank you for your help. If you would you like to be sent a copy of the findings of this study please tick this box . If you want to be sent the findings and have returned the questionnaire by post, please give us an address.

Maggie Ponder and Helen Statham

3. Handsel Trust Conference

One-day - handseltrust - Conference Monday September 20th 2004, Postgraduate Centre, City Hospital, Birmingham
Planning Family Support *Innovation & Excellence*

Speakers:

Peter Limbrick

Chair of the Handsel Trust and author of 'The Team around the Child' and 'An integrated pathway for assessment and support' on '**Good practice in assessment of need**'

Walsall Child Development Centre

This CDC has been using the Team Around the Child model to good effect and will be talking on '**Assessment of need within the TAC system**'

Susannah Botting & Adam Walker

From Triangle Services on '**Getting it right, consulting and involving disabled children and young people**'

Workshops include...

Lisa Jones of the Family Keyworker Team in Leeds on '*an integrated needs assessment tool*'

Members of Walsall CDC on '*assessment of need within the TAC system*'

Dr Angela Thompson of ACT on '*making a pathway through uncertainty and beyond – supporting families of children with life limiting / life threatening conditions*'

The role of CDCs in assessment of need of children with complex needs – *to be announced*

Examples of Family Service Plans – *to be announced*

Conference aims: - To discuss principles and practice in assessment of need of babies, children and young adults who have disabilities / special needs and their families.

- To consider current guidance and legislation.

- To disseminate information about examples of good practice.

The conference will be of interest to managers and practitioners in health, education, social services, the voluntary sector, parents, members of user-families, and representatives of parent and user organisations

Costs: A single place for a paid worker - £110 A paired-place for a worker & family member* - £160

**The 'paired-place' facility enables a member of a user family to attend with funding from their council or health authority. Please make use of it if you can.*

Please get in touch if you would like to include information about your good practice in the conference pack, or if you have a good example of a Family Service Plan.

For further information, please call 0121 373 2747 or email handsel.trust@virgin.net

Handsel trust *promoting effective support for children with complex needs and their families* www.handseltrust.org Registered charity no. 1082546

4. 1 Voice - Communicating Together

"We are a small, national charity that brings together young disabled people who are non-speaking and their families. Many children have thoughts in their heads but are unable to voice them and need alternative methods of communication. It can take years of frustration, isolation and practice to become a good alternative communication aid user.

We bring together families at events around the country to enable parent/carers to share ideas, experiences and to learn from one another. Disabled children are able to meet other peers and we have a team of disabled adults who are role models for the children and their families. We have a team of volunteers at the events that range from disabled adults, speech and language therapists and interested professionals. Brothers, sisters and volunteers children join us for all events and the emphasis is on inclusion, communication and fun!

We also produce a newsletter; e-mail support group; family link programme and a web site. For more information contact info@1voice.info or look at our web site on www.1voice.info. Phone Katie on 0845 330 7862 for more details".

5. Conference: Heading for Inclusion

Nottingham Racecourse Conference Centre 20th September – 9.30am-4.00pm

Hosted by the Alliance for Inclusive Education in collaboration with Inclusive Solutions

COST - £135+VAT (£158.63) includes lunch and a copy of the latest publication from the Alliance for Inclusive Education – 'SNAPSHOTS OF POSSIBILITY' which is being launched at this conference.

PRESENTERS INCLUDE:

Julie Vaggers – Head Teacher, Rowland Hill Centre for Childhood, London

Sue Eagle – Head Teacher, Tuckswood First School, Norwich

Rona Kennedy – Head Teacher, Kirkhill Primary School, Glasgow

Kenny Fredericks – Head Teacher George Green's Secondary School, London

Keith Brondwood & Ann Harwood – Curriculum Support Mangers, Blackburn College

Over the past year, the Alliance for Inclusive Education has been researching the best of mainstream school inclusion in the UK. This conference is the culmination of that work and brings together Head teachers and school managers to talk about their leadership for inclusion.

Please complete the application form below and post to
Emma Pyatt, DBH House, Carlton Square, Nottingham, NG4 3BP.

Telephone 0115 9408550 Email: nottingham@dbhservicedoffices.com

WORKSHOP TITLE AND DATE.....

NAME.....

JOB TITLE.....

CONTACT ADDRESS.....
.....

EMAIL..... TEL.....

INVOICE ADDRESS (if different from above).....
.....

PAYMENT DETAILS

I enclose a cheque for: £..... /I enclose an official order for £
Please make cheques payable to: *Inclusive Solutions*

Making Inclusion Happen! www.inclusive-solutions.com

6. Parents have needs too!

PARENTS HAVE NEEDS TOO! The role of counselling services for families of children with special needs & disabilities.

This booklet, produced by '3Cs', a project of Ealing Mencap, aims to increase understanding of the emotional aspects of having a child with special needs and the help that counselling may offer. We hope that parents of children with special needs will find helpful the thoughts and feelings expressed by parents in the booklet and feel less isolated with their experience.

We also hope groups and agencies concerned with children with special needs and disabilities will find the booklet useful in considering the provision of counselling and other forms of support to parents.

Parents Have Needs Too! was produced with funding from the Home Office Family Policy Unit.

To request free copy, please write to: 3Cs,KIDS Chiswick Centre,9 Devonshire St, London W4 2JS or email: 3Cs-counselling@supanet.com

7. Inclusion Now - The Magazine of the Inclusion Movement in the UK

From The Alliance for Inclusive Education

If you believe that all children should be welcomed and supported in their local mainstream school then this is the magazine for you. It is a grass-roots publication written by ordinary people who have found themselves facing the extraordinary challenge of inclusion. The articles are fresh and new, sometimes controversial, sometimes funny, always informative. It brings the voice of the excluded into the heart of the debate about educational change.

Contents include: Examples of Good Practice, Hidden voices, Training Opportunities, Reviews of new resources, Debate on issues, Updates on Government policy and legislation, Poems, stories and letters

Inclusion Now is published three times a year by The Alliance for Inclusive Education in collaboration with Parents for Inclusion and Disability Equality in Education. As well as the print version, it is also available on audio tape, or text only by email or on disc. For more information on how to receive it regularly, contact the Alliance for Inclusive Education on:
Telephone: 020 7735 5277 Email: info@allfie.org.uk Website: www.allfie.org.uk

8. Seminar in Newcastle: The Team around the Child (TAC)

Newcastle United Football Club Conf. Centre Monday Oct. 11th 2004. 10 - 4 p.m.

This Interconnections seminar: THE TEAM AROUND THE CHILD AND THE MULTI-AGENCY KEYWORKER for babies and young children with complex needs and their families

This is the third in a series, which so far has included Birmingham and London.

There will be an explanation of the TAC philosophy and practice with presentations by TAC projects at Halton Child Development Centre (Runcorn and Widnes) and Walsall Child Development Centre (the Midlands). Discussions will cover how TAC –

- Enhances multi-agency service co-ordination
- Promotes the central role of parents
- Provides a mechanism for the integration of programmes
- Gives the multi-agency Keyworker a clear and limited role
- Offers a joint assessment process
- Promotes **Together from The Start** principles and practice

Costs are on a sliding scale to facilitate team bookings with a single place costing £180 and group-bookings of 5 or more at £100 each. For information and booking forms please contact: Interconnections, Peter Limbrick, 9 Pitt Avenue, Worcester, WR4 0PL Tel/fax: 01905 23255, E-mail: p.limbrick@virgin.net

9. SIGNALong Update Newsletter

“Signalong publishes its newsletter SIGNALong UPdate twice yearly, giving information about new developments in sign-supported communication for children & adults with learning difficulties and autism, plus exhibition diary, the occasional book review etc. To get onto our mailing list email mknard@signalong.org.uk or write to The Signalong Group, Stratford House, Waterside Court, Rochester ME2 4NZ”

10. UK Health Care and Learning Disability Network

“Anyone interested is welcome to join this network - the only requirement is to have email. Lots of information and contacts nationally relating to health issues & learning disability. If people are interested in joining just need to mail Janet Cobb on janet.cobb@nwttdt.com Janet works for the North West Training and Development Team www.nwttdt.com”

Please forward this bulletin to interested colleagues and relevant networks and please get in touch if you have information to disseminate or questions to find answers to

Peter Limbrick. 9 Pitt Avenue, Worcester, WR4 0PL. Tel/fax: 01905 23255
E-mail: p.limbrick@virgin.net

NEWS, PUBLICATIONS AND RESOURCES



Children with complex support needs in healthcare settings for long periods

JRF Report July 2003

Anecdotal evidence suggested there may be significant numbers of children and young people spending long periods in healthcare settings such as hospitals and nursing homes. This study, by a research team from the Universities of Stirling, Durham, Newcastle and York, explored the experiences of 15 children and young people in a variety of healthcare settings. The team also mapped all discharges of children and young people from birth to 19 years of age from all NHS hospitals and healthcare settings in England and Scotland during a twelve-month period. The study found that:

- During the twelve months studied, this age group accounted for over two million 'bed days' in England and 115,000 in Scotland. Teenagers with 'mental health and behavioural problems' in England were the group most likely to have been in hospital for one year or more.
- A few children and young people were found in nursing homes and children's homes registered with health authorities.
- Confusion exists among some service managers and providers in health and social services about the legal status of children and young people in healthcare settings for more than three months.
- There was no agreed definition of 'complex needs' among professionals, and thus no clear picture of the numbers of people who might fall into such a group. It was not possible to identify children with complex needs from the data provided by hospitals.
- Within the learning disability hospital and the residential school in the study, little evidence existed of clear procedures for consulting children and young people, particularly those with communication impairments, about aspects of their care and treatment.
- Few of the young people involved had access to a social worker. None had an independent advocate. Parents and professionals identified several barriers to discharge from healthcare settings, including lack of funds for housing adaptations, and a shortage of occupational therapists and specialist nurses in the community.

New services designed to facilitate the discharge of children and young people from medical wards and to support them in the community had been set up in three of the fieldwork areas.

New Name for Holiday Care
The new name is Tourism for ALL, for more information: www.tourismforall.info or 0845 124 9971
Newsletter handseltrust
The Handsel Trust promotes effective support for families who have a child with disabilities/special needs. Tel/fax: 0121 373 2747 Handel.trust@virgin.net

OTHER RESOURCES

Early Support

This is a pan-disability national initiative funded by DfES to develop and identify effective service provision for young children. They have developed 4 sets of materials:

- Early Support Family Pack
- Early Support Materials for Professionals
- Early Support Service Audit Tool
- Early Support Developmental Profile for deaf children to find out more:

www.espp.org.uk
or contact Liz Gutteridge at RNIB
0121 665 4221

Carer's Guide to Physical Interventions and the Law

Prof. Christina Lyon and Alexandra Pimor

An overview of the law and physical information for care workers, parents and other informal carers.

ISBN 1 904082 81 5

£12.00

Mencap

http://www.mencap.org.uk/html/treat_me_right/index.htm

Mencap has produced a report entitled **Treat me Right**, which is about the quality of the health services, received by people with learning disabilities. They are also running a petition from their web site that you can read more about by accessing the above link.



Asbah <http://www.asbah.org/>

Asbah is the national charity for people with spina bifida and / or hydrocephalus and their families / carers. We have a network of local advisers to give people information about the conditions and about national and local services and benefits available to them and to help them access these. We have access to specialist backup on medical / nursing issues and education.

We also run periodic courses and study days for families and individuals.

Our Northern Region office is at Asbah House North, 64 Bagley Lane, Farsley, Leeds LS28 5LY, tel. no. 0113 255 6767, email nro@asbah.org

In the N. West we have the following advisers:

- Greater Manchester - Marcia Conroy - 0161 864 1394
- Wirral and Cheshire - Elizabeth Miers - 01290 450360
- Cumbria, N. Lancs. - Moira Foggo - 01228 536880
- Merseyside (except Wirral), S. Lancs. Angela Lansley - 0151 733 8392. lansley@surefish.co.uk

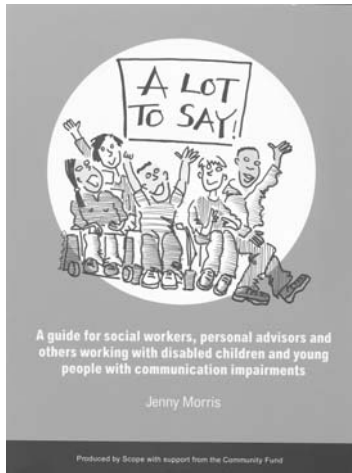
Please feel free to circulate anything that may be of interest and let us know if you or anyone else should want any leaflets from us. Angela

All together better

The Family Fund has published a new guide for families of a disabled child with complex health care needs.

The booklet is available in PDF format on the website, (www.familyfund.org.uk). 'All Together Better' draws on the experiences of families interviewed as part of the Working Together research project. www.familyfund.org.uk or <http://www.bris.ac.uk/Depts/NorahFry>



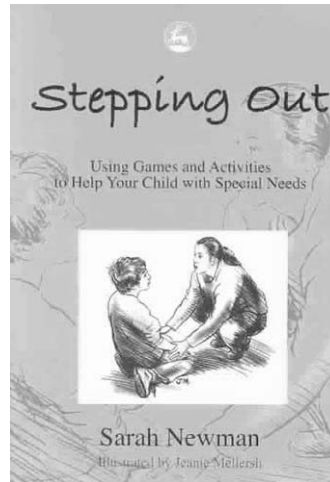


A Lot to Say

Jenny Morris

A guide for social workers, personal advisors and others working with disabled children and young people with communication impairments

ISBN 09446828423
Available from SCOPE
Free but limited to 20 copies per order

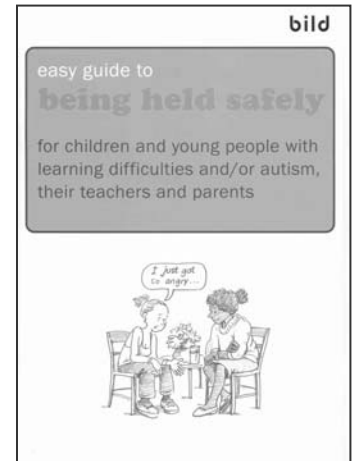


Stepping Out

Sarah Newman

Using Games and Activities to Help your Child with Special Needs

From RNIB, Customer Services:
0845 702 3153
Ref: ED414 £14.95



Easy Guide to Being Held Safely

The booklet covers being held for children and young people with learning difficulties and/or autism.

ISBN 1 904082 71 8
BILD Member: £4.50
Full Price: £5.00

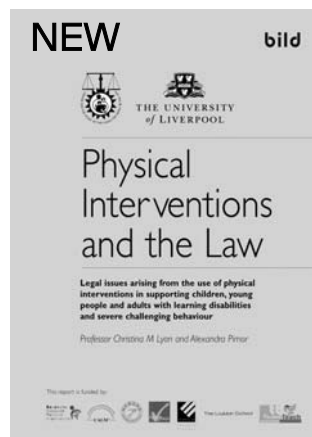


Moving On: Supporting Parents of Children with SEN

Alison Orphan

A resource for running 10 group sessions for anyone working with parent groups

David Fulton Publishers
ISBN: 1 84312 113 1
Full Price: £17.50



Physical Interventions and the Law

Prof. Christina Lyon and Alexandra Pimor

An overview of the law and physical interventions in the United Kingdom.

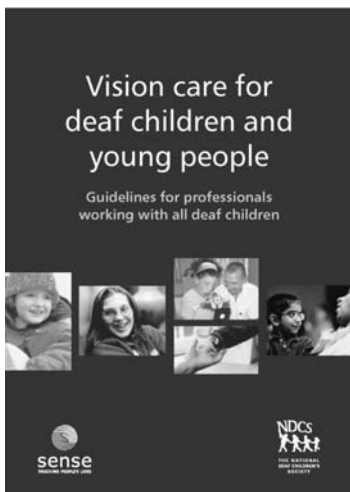
ISBN 1 904082 73 4
BILD Member: £16.20
Full Price: £18.00



Getting Older - Feeling Good

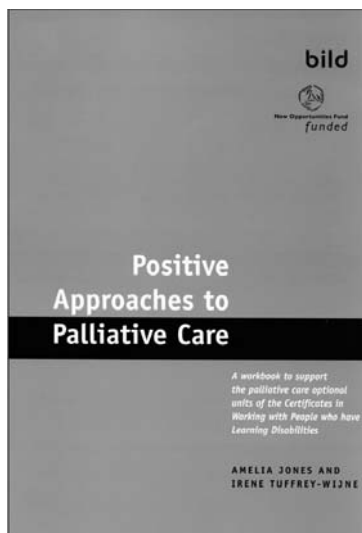
Latest Edition to Your Good Health series by BILD. Designed to inform people with a learning disability about health issues.

ISBN 1 904082 70 X
BILD Member: £4.95
Full Price: £5.50



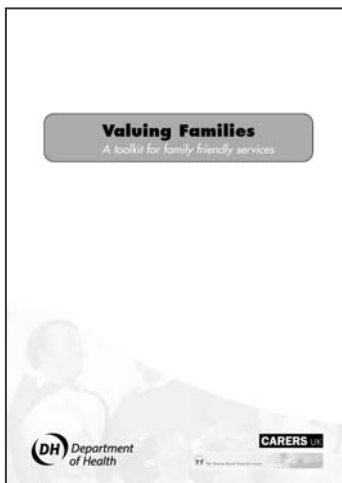
Vision care for deaf children and young people

New guidance for eye care professionals from the National Deaf Childrens Society (NDCS) and Sense. Copies can be downloaded from the sense website: www.sense.org.uk or call NDCS for a free copy: 808 800 88800



Positive Approaches to Palliative Care

Amelia Jones and Irene Tuffrey-Wijne
A study workbook to support people undertaking the optional units the level 2 and level 3 Certificates in Working with People who have Learning Difficulties
ISBN 1 904082 53 X
BILD Members: £10.80
Full Price: £12.00

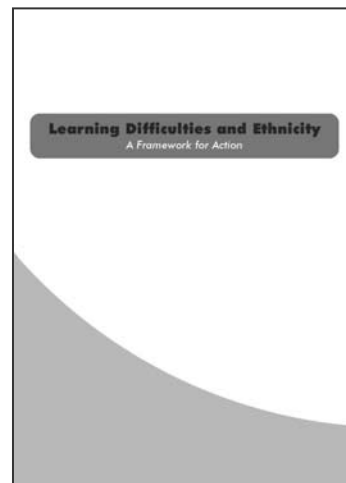


Valuing Families Toolkit

by Valuing People

A toolkit to help Learning Disability Partnership Boards improve their support to family carers.

Valuing families is available to download from: www.doh.gov.uk/vpst

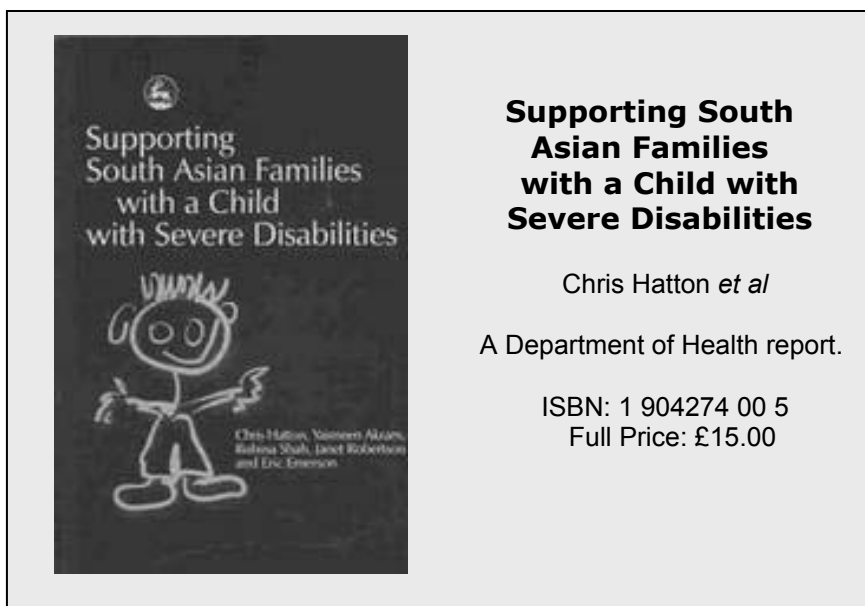


Learning Difficulties and Ethnicity: A framework for Action

By Valuing People

The document is to provide best practice in ensuring that the objectives of Valuing People apply equally to people with learning difficulties

Valuing families is available to download from: www.valuingpeople.gov.uk/documents



Supporting South Asian Families with a Child with Severe Disabilities

Chris Hatton *et al*

A Department of Health report.

ISBN: 1 904274 00 5
Full Price: £15.00

EXHIBITION

Pavilion - Learning Disability Today London 2004 exhibition

Date: Wednesday 24th November 2004
Venue: Business Design Centre, London

Learning Disability Today London features 130 exhibitors, a contemporary seminar programme and keynote panel discussion focusing on 'Supporting Citizenship' from some of the leading specialists within the sector, plus the very best in learning disability art, theatre, music, media and technology.

All for just £15.
Group discount: 5 for the price of 4 - that's just £60

Free attendance for service users: please apply in writing
A chance to get together with thousands of your peers to learn, share and enjoy the latest developments, news and innovations.

The Hearing and Sight Centre Exhibition is Back! - 08.10.2004

Our 2004 exhibition of equipment and services will be held on Friday 8th October 2004 at Plymouth Guildhall from 10.00am-4.30pm.

NEWS FROM NASEN

The Toolkit to support SEN provision in the Early Years is now available and can be ordered from the DfES.

It is free. Details below
Prolog – DfES publications
PO Box 5050
Sherwood Park
Nottingham
NG15 0DG

INFOMATION EXCHANGE MAGAZINE

This multisensory magazine has been going since the 1980s and is run by volunteers with Flo Longhorn the managing editor. It is full of contributions from families and professionals, lots of fun and ideas and thought provoking ideas as well.

Out 3 times a year.

For a sample copy or subscription form contact flocatalyst@aol.com or 01234 764108

Practical Resource recommended by a parent

People who are searching for dignified and age appropriate bibs. Have a look at: www.shepherdess-carewear.co.uk

I have purchased a few of their products and have found the service is excellent as the product

ALSO OUT NOW

Planning music for children with Learning Difficulties. A guidance booklet for teachers working in Hampshire special schools

L Davies

A guidance booklet for teachers working in Hampshire special schools

Call RNIB Customer Services:
0845 702 3153

Ref: ED419 £8.00

'Play Talks' pack

by Scope

An Early Years communication pack for parents and professionals to promote communication through play.

For more information and/or Play Talks pack contact: Cara Davies:
02920 662 402
or email:
cara.davies@scope.org.uk

£15.20

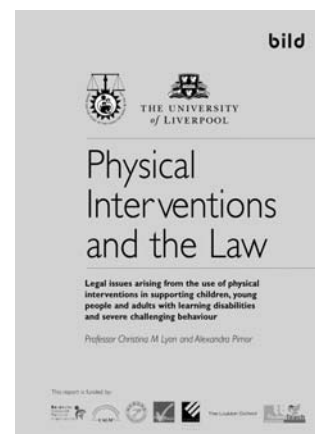
Review

Physical Interventions and the Law: Legal issues arising from the use of physical interventions in supporting children, young people and adults with learning disabilities and severe challenging behaviour.

Professor Christina M. Lyon and Alexandra Pimor (2004)
Kidderminster: Bild

ISBN: 1 904082 73 4
£18.00 (£16.20 Bild members)

This report is now probably the most comprehensive and informative literature on legal issues arising from the use of physical interventions with children and adults with learning difficulties and severe challenging behaviour. It provides a wealth of information that applies to parents, carers, and those working in Education, Health and Social Care. The contents are extremely relevant to parents, carers, teachers, teaching assistants, and those working to support the needs of children and adults in all multi-professional settings. The new report clearly defines the differences between English and Scottish law.

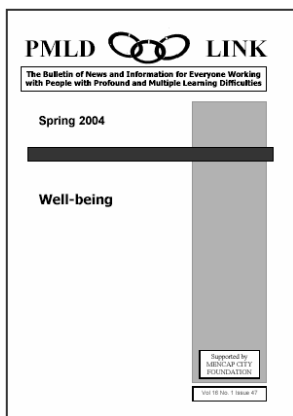


It contains detailed definitions of key concepts such as the rights of the child and adults as well as parents and carers. The report also provides definitions of challenging behaviours including aspects relating to their causes, our myths and prevention strategies. The section of legal issues considers the range of legislation by examining the guidance provided by the Department of Health and DfES and includes a breakdown of the 550A education Act 1996 and circular 10/98 as well as more recent guidance.

I would strongly recommend that all local education authorities and service providers become familiar with the section on Employer's responsibilities, as this is crucial to safeguarding their employees and the children and adults they work with. The report discusses civil law and human rights Law for England and Scotland. It then goes on to include a range of insightful and informative case studies using examples from carers, parents, therapists and other professionals across a range of services and organisations.

I would strongly recommend this report to all those who work with children and adults with learning difficulties and severe challenging behaviours.

Steve Cullingford-Agnew
Centre for Special Needs Education and Research (CeSNER)
University College Northampton.



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Short Courses and Conferences

CONTACT DETAILS

BILD

Campion House, Green Street,
Kidderminster, Worcestershire
DY10 1JL

☎ 01562 723025

E-mail: learning@bild.org.uk

Catalyst Education Resources Ltd

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

Further details:

☎ 01234 764 108

E-mail: FloCatalyst@aol.com

Web: www.cerl.net

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Clent Grove, Clent,
Nr. Stourbridge, West Midlands
DY9 9PB

☎ 01562 883183

E-mail:

Sunfield@sunfield.worcs.sch.uk

University College Northampton

Further details:
Centre for Professional Development in
Education

☎ 01604 892695

Fax: 01604

E-mail: cpde@northampton.ac.uk

Cost: £90 (including Lunch)

University of Manchester Institute of Science and Technology

Alison Littlewood

☎ 01457 819790

E-mail: alison.littlewood@atandi.org

Short Courses

Epilepsy Awareness

- Kidderminster Sept 20th 2004
Sheffield Nov 1st 2004
London Jan 31st 2005

booking forms and details available from
Bild.org.uk

Meeting the Needs of People with Profound Learning Disabilities

London	Sept 20 th 2004
Kidderminster	Oct 18 th 2004
Sheffield	Nov 22 nd 2004
Swindon	Dec 6 th 2004

Booking forms available through Bild.org.uk

29th September

Managing incidents of challenging Behaviour and working towards having less of them

Dave Hewett
(Freelance Trainer and consultant)

Sunfield PDC: Course no. PDC/050/04
Course Cost £110



4/5 November 2004

Catalyst Education Resources

2 day residential workshop in Central London
Working with teenagers and young adults with
profound disability – learning for life

Further details from 0845 127 5281 or
www.cerl.net

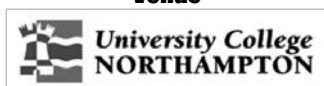
29th September

NEW SENCO Course

Management of Staffing, National Initiatives & Administration

Since the introduction of the Code of Practice on the Identification and Assessment of Special Educational Needs in 1994 the role of the SENCo has considerably evolved. In all schools the SENCo holds an important position in that their function is to co-ordinate the school's policy and provision across the whole curriculum. The 2002 Revised Code of Practice is very clear when it states that this role is a key management post; to reflect this whole-school responsibility many schools have included the SENCo as a part of their Senior Management Team. This one-day programme of study is primarily designed for new SENCos and examines this increasing 'management' role.

Venue



Price

£90 (including Lunch)

18th November

Interactive Approaches

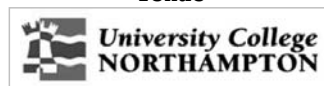
for Pupils with Autistic Spectrum Disorders

With

Christine Reeve & Kyffin Jones

Interactive approaches are gaining prominence in the field of autism. Historically they were advocated for with children with severe learning difficulties. This course aims to describe the nature of interactive work and to demonstrate how it may be successfully implemented for children with severe learning difficulties, but also children with autism and Asperger Syndrome. It will be relevant to all staff working with children who have social and communication difficulties.

Venue



Price

£90 (including Lunch)

23rd November

Promoting a learning Environment – Perspectives in Practice

Tricia Barthorpe

Sunfield PDC: Course No. PDC/065/04
Course Cost £110



15th October

Sherbourne Developmental Movement 'Taster Day'- Introductory Basic Course

Cyndi Hill
(Sherbourne Consultant)

Sunfield PDC: Course No. PDC/065/04
Course Cost £97.50



Flo Longhorn

A series of Workshops on assessing the earliest levels of Learning including bio behaviours, sensations, latest on brain development and setting up your own assessment kit.

Leeds 19th November
Liverpool 29th November

Swindon 26th November
London 3rd December

Conferences

26th November

Enabling participation of children and young people with severe and profound and multiple learning difficulties

BILD working in partnership with Mencap (Booking forms and prices from www.Bild.org.uk)

The theme of this conference is enabling meaningful participation of children and young people with severe and profound and multiple learning difficulties.

There is now general consensus – endorsed by legislation and central guidance – that the participation of children and young people with severe and profound and multiple learning difficulties in issues and activities affecting their quality of life is a good and desirable goal: the revised Code of Practice (DfES 2001a) and the support information in the SEN Toolkit (DfES), for example, both place an emphasis on participation. Similarly, global initiatives such as the United Nations Convention on the rights of the child give children and young people the right to active participation in decision-making about their own lives.

Through a selection of topical and stimulating keynote speakers and participatory workshops the concept of participation will be explored and relevant issues will be addressed, including:

- how is the concept of participation by children and young people with severe and profound and multiple learning difficulties being addressed nationally?
- in what contexts and settings might meaningful participation be most likely to occur for children and young people with severe and profound learning difficulties?
- what are some of the activities in which they might meaningfully engage and what are some of the approaches which might be used to promote participation?
- what support systems and mechanisms are available to children and young people with severe and profound learning difficulties which will help to enable their meaningful participation?

The conference is based on the successful journal 'The SLD Experience' and will be of interest to a multidisciplinary audience of practitioners in education, health and social services as well as family members.

The Oxford Hotel, Oxford



Conference - Planning Family Support

'Innovation and excellence'

Birmingham, Monday September 20th 2004

The conference will focus on assessment of needs and family support plans. Discussion will include the role of CDCs, the voice of the child, empowerment of parents and multi-agency working.

To find out more about the conference please contact the Handsel Trust, 62 Johnson Road, Erdington, Birmingham, B23 6PY, Tel/fax: 0121 373 2747. E-mail:

handsel.trust@virgin.net

Please also visit: WWW.handseltrust.org

The editor of the next PMLD LINK is
Ann Fergusson

'Assessment'

The copy date for all articles, information and news for the Winter issue is the **1st November 2004** and the focus is on **'Assessment'**. Don't forget to send all contributions to Ann Fergusson preferably in RTF (Rich Text Format) or 'Microsoft Word' (Ann's contact detail are on the next page). If you are also able to supply photographs to enhance your article please do so, but it is important that the relevant permission to publish is obtained beforehand.

4th November
Valuing Good Practice in Autism

The Good Autism Practice (GAP) conference is based on the successful foundations of **Good Autism Practice (GAP)** journal, which provides a platform for acknowledging and sharing good practice in autism. The conference aims to meet the needs of practitioners and parents living or working with individuals with autistic spectrum disorders of all ages. The conference will be of interest to a multi disciplinary audience for professionals inservices provided by health, social services and education as well as parents and individuals with autistic spectrum disorders.

The conference aims to disseminate good practice, raise issues of relevance to practice and to facilitate a reflective and evaluative approach to practice.

This will be achieved through a selection of stimulating and thought provoking keynote speakers and workshop sessions which cover a range of current key issues for those involved with autistic spectrum disorders.

The Majestic Hotel, Harrogate



12th November
Catalyst Education Resources Ltd

3rd Annual Conference 12th November – Manchester with the theme “Profound disability: opening the door”

Keynote Speaker: Robert Orr

Contact:
 01234 764 108 or flocatalyst@aol.com

23th November
Valuing staff & service users:
working together to develop the workforce

The government is committed to ensuring that social and health care staff working with people with learning disabilities are appropriately skilled, trained and qualified. We need to be confident that all people working in this field are equipped to work in the new ways required by the strategy in ‘Valuing People’ 2001 and that in future, all people working with or dealing with people with learning disabilities are:

- Better trained and qualified with a commitment to life long learning
- Skilled at working in partnership with users and carers
- Confident in working in multi-professional teams, and across agency boundaries
- Culturally competent _ Part of a local workforce and services which represent their communities
- Well led and managed

This one day conference enables practitioners, professionals, managers, policy makers, service users, parents and carers to explore issues relating to workforce training and development for adults and children with learning disabilities.

This will be achieved through a selection of stimulating and thought provoking keynote speakers and workshop sessions which cover a range of topical issues.

Chesford Grange Hotel, Kenilworth



24th and 25th September

£30 Each Day

Quality Communication:

Maximising Opportunities for People with Multi-Sensory Impairment

The conference is suitable for teachers, advisory and support teachers, intervenors, teaching assistants, parents, and other professionals who work with pupils with Multi Sensory Impairment. The two days have been subsidised by the East Midlands Regional Partnership. The conference will take place over two days and participants are welcome to attend one or two days.

For further enquiries contact:
Charlotte Dale
East Midlands SEN Regional Partnership,
C/o GOEM

E-mail: CDALE.GOEM@go-regions.gsi.gov.uk
Tel No: 0115 9712543
Fax: 0115 9712414

Venue



Keynote Speakers

Barbara Miles
Communication Specialist Consultant USA

Paul Hart
Sense Scotland

Eileen Boothroyd
Sense-National Education Officer

John Shaw
Joint Agency Services Manager
Exeter Primary Care Trust Devon

LONGER COURSES (with accreditation)

Interdisciplinary work with People with Profound and Multiple Learning Disabilities

A one year distance education course for practitioners and carers of children and adults with profound and multiple learning disabilities. The main focus is upon lifelong learning, communication and effective interdisciplinary collaboration. Offered at three levels: Post experience certificate (level 1), Advanced Certificate (level 3), Postgraduate diploma and Masters (level M) Further details: University of Birmingham, School of Education Tel: 0121 414 4866

M.Sc/PG Diploma in Learning Disability Studies

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

This course meets the training needs of a variety of professionals involved in delivering services to children or adults with a learning disability, including registered nurses, social workers, doctors, occupational therapists, physiotherapists, speech and language therapists, officers in statutory, voluntary or private establishments, FE tutors, staff of SECs. It provides the opportunity to participate in and contribute to inter-disciplinary learning in a collaborative setting. Further details: Helen Bradley, course director, University of Birmingham, School of Medicine, Tel: 0121 415 8118

Profound Learning Disability and Multi Sensory Impairments

A two-year course for parents, carers and professionals which will develop skills and obtain recognition for them. Work is home based, supported by workshops and telephone tutor support. Issues relating to challenging behaviour, communication, education, ordinary life principles, sensory impairment, interdisciplinary working and epilepsy are addressed. The course is offered at three levels: Undergraduate Certificate, Postgraduate Diploma and Masters.

Further details: University of Manchester Faculty of Education Tel. 0161 275 3337 E-mail: JTI.Office@man.ac.uk www.education.man.ac.uk/pmlD/

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

CHESL: 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

MSc in Learning Disabilities - distance learning course covering all aspects of learning disabilities, however with a strong accent on adults. Consists of nine modules, dissertation and Viva. Each module is assessed by written assignments of varying sizes from 1500 words to 4000 words at level M. Further details: Stuart Cumella/Helen Bradley at the Medical School, Birmingham University.

ACE/Post Grad. Dip/Bphil./MEd.**An Interdisciplinary Approach to Learning Difficulties (Severe, Profound and Complex)**

A brand new course is planned to commence Sept 2004 in the School of Education at Birmingham University. It will consist of a number of modules and a dissertation depending at which level you are studying. The course is by distance learning methods with tutorial support. Further details: Penny Lacey at the Education School, Birmingham University.

Certificate in Working with People who have Learning Disabilities

Distance learning courses from BILD for staff working in the learning disabilities field. Wide range of units available for study. A tutor throughout the course supports each student. Further details: BILD Learning Services Tel: 01562 723010

Certificate in Working with People who have Learning Disabilities: your pathway to achievement

The Learning Disabilities Award Framework route to qualification for staff supporting people with learning in disabilities. A course programme and supporting materials, including a trainer's toolkit and student workbook.

Available from Pavilion Publishing Tel: 01273 623222 or e-mail: info@pavpub.com

Report Back

Communication and PMLD - What's New? A Conference at Penhurst School, 9th June, 2004.

Janet Trebilcock
Specialist Speech and Language Therapist (PMLD)

Apologies to anyone who couldn't get a place at this conference, because those of us who were there had a great day! It was such a privilege to have an opportunity to network with Speech and Language Therapists, teachers and other people working in this very special field of PMLD. There was a real buzz of excitement around Penhurst, not just from people having a nice day out in the country (although they were!), but from a sense of pride in belonging to a field that is given exciting research opportunities, with experienced practitioners willing to enthusiastically pass on their expertise and ideas.

We were thrilled to welcome **Nicola Grove**, Senior Lecturer at City University, London, who gave an inspiring keynote speech on "Storytelling for all", and then led a workshop on practical strategies on the same theme. She stimulated much thought around the importance of recognizing, recording and retelling significant life events in a meaningful and interesting way, to promote areas such as memory, identity, fun and friendship. Nicola's own lively storytelling captivated the audience, many commenting that they could have listened to her all day.

A variety of workshops were on offer throughout the day. **Tony Jones**, the managing director of Liberator, as well as providing a stunning display of wares, led a very popular session on "Multi-sensory Referencing", which gave much food for thought on using objects of reference in a Total Communication Environment. **Liz Hodges**, Lecturer In Multi-Sensory Impairment at Birmingham University and Advisory Teacher for Deaf/blind Children in Herts., gave fresh insights and down-to-earth ideas on "Making Choices Real". It was challenging to reflect on the how, when and why of offering choices, and avoiding many pitfalls along the way. Audience participation was the order of the day in a session led by **Maggie Craig** (Specialist Teacher, Visual Impairment Service, Cambridgeshire). Her theme of "Movement and Voice" generated much discussion and good-humoured controversy as delegates pondered the impact of the session on their practice. A Valliant effort from **Gillian Bolton**, who brought her 4-week-old son with her, completed the line-up. Gillian is a SLT from Rugby and was introducing her training package "Assessing and Promoting Effective Communication - APEC", which can be used as a tool to train staff to use Latham and Miles' "Assessing Communication" framework. The new edition of the pack includes accompanying video and audio material.

A large gathering of like-minded professionals is a great opportunity to share new ideas, so it was a pleasure to give the floor to **Helen Francis**, SLT at St. Margaret's School in Tadworth, and **Stacey Lawrence**, SLT at Northwick Park Hospital, who gave information on the new SLT PMLD Special Interest Group and E-Network. If you are a SLT interested in joining that group, contact Stacey at Stacey.Lawrence@nwlh.nhs.uk.

Also brand new is the AAC Curriculum due to be published on the SCOPE website in September. This curriculum has a PMLD section, which was presented in fine style by representatives from the team who have produced it - **Gillian Hazell** (SCOPE), **Clare Latham** (SLT at the ACE Centre, Oxford), **Ann Miles** (teacher at The Redway School) and **Richard Walter** (teacher at Meldreth Manor School). The curriculum is built around the P level framework, and includes an assessment section and activity framework, with sample activities illustrating diversity in the classroom in a very practical way.

At the reflective plenary session, the chatter was animated as delegates discussed how to put into practice all the ideas they had heard. We hope that time and energy will be found for ideas to be translated into reality!

Thank you to Penhurst Staff who acted as hosts, Oxfordshire Speech and Language Therapists who chaired the sessions, all our presenters (including QED and NCH for providing quality displays), and of course to Rosemary, Penhurst's Domestic Bursar, for a fantastic lunch! Penhurst are hoping to make this conference a biannual event, so watch out for publicity early in 2006, and book quickly to avoid disappointment!

Janet Trebilcock
Specialist Speech and Language Therapist
(PMLD)
Penhurst School, New Street, Chipping
Norton, OX7 5LN