

PMILD



LINK

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

Spring 2004

Well-being

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PMLD LINK

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

Well-being

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

The editor of the next PMLD Link is Di Foxwell.

The copy date for all articles, information and news for the Summer/Autumn issue is the 1st July and the focus is on 'Quality Services'. Don't forget to send all contributions to Di Foxwell preferably in RTF (Rich Text Format or Microsoft Word (her contact details 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

It is important that readers refer to each issue of the Bulletin for the latest information on 'who is doing what' in the gradual process of Carol's stepping down.

GUEST EDITORIAL

Spring 2004

This issue of PMLD Link marks the beginning of a new era. You will have read in the last issue that Carol Ouvry is 'stepping down' as editor, publisher, administrator and head cook and bottle washer (!) and the production of PMLD Link is now being undertaken by staff at University College Northampton. Such moves have meant that the issue has a rather different 'look' as the editor and the production team find mutually suitable fonts, design and hardware to transfer the content of the Bulletin from one machine to another.

I am the first 'guest editor' and I am grateful to all members of PMLD Link's Advisory Group for their help in obtaining articles and providing advice and support with this challenging task. The standard that Carol has set over the years has been very high and without her commitment and enthusiasm PMLD would never have developed in the way that it has. It has become *the* publication for those working in the PMLD field and, thanks to Carol's hard work, is highly regarded by parents, staff of schools and services, lecturers, researchers and administrators. We all owe you a tremendous debt, Carol, and we wish you a happy and well deserved stepping down, with plenty of time for you to be with family and friends. Carol's stepping down is a gradual process and you will see that she is still looking after subscriptions, information and enquiries!

In this issue of PMLD Link the majority of articles focus on the theme of well being. The first two articles complement each other and raise many important points for consideration. We have an exciting mixture of research findings, information, practical examples and reports on new resources. We are also privileged to have an overview by Philippa Russell on '*Removing Barriers to Achievement: The Government's Strategy for SEN*', which has recently been published. Many of the issues raised in Philippa's article resonate with the theme of well-being and complement topics raised in the articles by the other writers.

I hope you enjoy the issue.

Christina Tilstone

Subscriptions, information and enquiries

Carol Ouvry
The Old Rectory
Hope Mansell
Ross-on-Wye
Herefordshire HR9 5TL
Tel: 01989 750870
PMLD@mansell.wyenet.co.uk

Articles, News, Reports, Letters Summer/Autumn Vol. 16.2 Issue 48 Quality Services

Di Foxwell
50, Boness Road
Wroughton
Nr. Swindon SN4 9DT
di@phonecoop.coop

Reviews

Ann Fergusson
University College Northampton
Park Campus
Boughton Green Road
Northampton, NN2 7AL
Tel; 01604 735500
Ann.fergusson@northampton.ac.uk

Production

Paul Bramble,
University College Northampton
Park Campus
Boughton Green Road
Northampton, NN2 7AL
Paul.bramble@northampton.ac.uk

Articles, News, Reports, Letters Winter Vol. 16.3 Issue 49 'Assessment'

Ann Fergusson
University College Northampton
Park Campus
Boughton Green Road
Northampton, NN2 7AL
Tel; 01604 735500
Ann.fergusson@northampton.ac.uk

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

Quality Services and People who have Profound and Multiple Learning Disabilities

'We live in a society that sees people like my daughters as worthless. Why then would it be one that delivered high quality services?' (No Ordinary Life, Mencap 2001)'

These are the words of a parent of two daughters, both of whom have profound and multiple learning disabilities, from a family whose experience of quality had been anything but high! In fact, they could tell you about a shocking array of experiences that led them to believe that the sort of services, to which they felt their daughters had a 'right', were unobtainable.

Their statement also expresses the view that if we are to deliver high quality services to those with profound and multiple learning disabilities we must value them as people. This was one of the principles that underpinned the report written by the PMLD Network, *Valuing People with Profound and Multiple Learning Disabilities* (PMLD Network 2001). The content of the report suggests that if we want to increase quality we need to start by taking a close look at our own values.

In a society where people may make judgements on the meaning and quality of someone's life, and use this information to make decisions about the nature and quality of the services that can be offered, we can all find ourselves challenged by the whole notion of 'quality'. We also find that, with the best of intentions, some of the aspects used as criteria for quality in services are not necessarily appropriate, for example, placing too much importance on how a person is progressing towards independence. When we are considering the needs of someone who may be experiencing the world from a very different perspective, it may be that we need some *other* or *additional* criteria in judging quality.

It is all of this, and more, that is the focus of the next edition of PMLD Link. We would like to hear of your ideas:

How have you gone about measuring the quality of the services you offer?

How have you involved children and adults with profound and multiple learning disabilities in developing quality standards in your organisation?

Do share your ideas; we look forward to hearing from you.

Beverley Dawkins
National Officer for Profound and Multiple Learning Disabilities, Mencap.
Email: Beverley.dawkins@mencap.org

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Count Us In

Navigating the transition from school to adult services for young people with learning disabilities can be exceptionally stressful. Major decisions are usually made as to what happens to the young person when they leave school, and what options are available if they want to leave the family home. During this period families and professionals are often so busy focusing on these aspects that another important area of the young person's life can be neglected – their mental health needs.

Mental health refers to a sense of emotional well-being including self-esteem, optimism, being able to cope with adversities and to develop and sustain mutually satisfying relationships (*Count Us In*, 2002). This article also considers mental health problems, and refers to those levels of emotional, psychological and psychiatric distress that present significant challenges to people. Whilst work has been conducted into mental health problems experienced by people with mild learning disabilities, little work has been undertaken on the emotional needs of people with severe or profound and multiple learning disabilities.

The Count Us In Inquiry

With this in mind, in 2001 the Foundation for People with Learning Disabilities convened an Inquiry to explore the mental health needs of all young people with learning disabilities. Focusing on people aged 13-25 years, the Inquiry sought to examine the needs of a group who are four times as likely to develop mental health problems as others their age. The result of the year-long inquiry is the report *Count Us In*, which was generously funded by the Baily Thomas Charitable Fund.

The Inquiry committee was made up of professionals from clinical and academic backgrounds working within health, social services, education and research organisations and was chaired by Professor Barry Carpenter. In addition to the committee, the Foundation was advised by two members from Generate, an advocacy group for people with learning disabilities. The two advisers, Emma Wilson and David Green, reported from focus groups with other young people in a variety of settings, including a special school, a college, and an advocacy group to find out what they value most.

This article summarises some of the key issues of the report and describes the early findings of the Well-Being project, a piece of research funded by the Foundation that is

addressing the needs of young people with profound and multiple learning disabilities.

Evidence to the committee

The Foundation heard from more than 250 families and professionals who also contributed to the Inquiry by providing written evidence about their experiences. This enabled the Foundation to gain a picture of what services and interventions are available to young people throughout the UK.

The range of mental health problems experienced by young people with learning disabilities is similar to the general population. However, young people with learning disabilities are far more likely to develop emotional difficulties such as depression and anxiety. Experiencing these types of problems can have a significant impact on relationships and negotiating the transition to adulthood.

Risk factors and factors promoting good mental health

The most common risk factors for developing mental health problems have been identified. They include low self-esteem, abuse, racism, economic disadvantage and physical illness. The Foundation learned that as well as having a greater risk of developing mental health problems, people with learning disabilities

are at more risk of having physical problems, for example, epilepsy, hearing or visual impairments. Links between epilepsy and mental health problems in people with learning disabilities have been identified (King et al, 1995, Hogg, 1992). Given the high prevalence of epilepsy among people with profound intellectual and multiple disabilities, it suggests that this group of young people have a far greater risk of developing mental health problems.

The following evidence from a carer indicates how physical health can be a risk factor

‘There was late diagnosis of deafness and then delay in the provision of hearing aids and a failure to advise on sign language – this increased the likelihood of mental health problems.’

Those factors that promote good mental health include strong role models, early and practical support for families, decent income and good housing. Parents have told the Inquiry they would value more information on mental health in an accessible format (the Foundation have produced such information for parent/ carers and young people), to have confidence in professionals and in their procedures and be listened to.

Getting the right help

Some of the most common messages the committee heard were that young people encountered difficulties in getting appropriate services close to home if they experienced mental health problems, and of vague pathways to referral for help and support. This will come as no surprise to most young people, carers and professionals in the field. At present a lottery situation determines whether an individual is seen by a mental health or learning disability specialist, or in fact by anyone at all.

The Foundation heard that there were often long time delays to access assessment and interventions, young people were shunted between mainstream and specialist services

or not fitting in anywhere. One nursing manager quoted:

‘The most common approach to responding to the needs of this group is “no response” until problems have escalated to the point of significant risk.’

This is the time when young people are most vulnerable to developing mental health problems yet this is the point in time when it is most difficult to obtain help. Patterns of service delivery vary across the UK, a teenager presenting with a mental health problem could be referred to the local community paediatric service, the Child and Adolescent Mental Health Service or the Learning Disability service, depending on where he or she lives. The GP is often the first port of call yet mild conditions are not always recognised and treated, and GPs do not always refer those with more serious conditions for further help.

For those with profound and multiple learning disabilities, the signs may not be obvious and mental health problems may present as challenging behaviours. Challenging behaviour is generally related to some form of communication intent but it is important to consider that the behaviour may be caused by a mental health problem. One of the issues in identifying mental health problems in people with profound and multiple learning disabilities is that there are no suitable diagnostic tools available to clinicians.

The transition period

Moving from adolescence to adulthood is daunting for most young people and this is a time when many young people suffer a lack of confidence and experience confusion as to where their future lays. The process can be more daunting for young people with learning disabilities because many lack a local peer group or have communication difficulties that make it hard to talk about their feelings.

For some young people with the most complex needs, they may be attending a specialist school miles away from home

making it very difficult for them to be re-settled into a local service when they leave school. Early findings from the Well-Being project indicate that the transition from school to adult services can create anxieties in young people with profound and multiple learning disabilities.

Our advisers Emma Wilson and David Green, met with various groups of young people and informed us about what they value. The young people they met said they want to lead the same lives and experience the same things as other young people.

Recommendations from the Inquiry

The report makes several recommendations, some of the most important ones affecting the lives of young people with profound and multiple learning disabilities include:

- schools and colleges should aim to promote and sustain positive mental health in young people with learning disabilities.
- the transition from child and adolescent services must be seamless. Families and young people need to be fully informed about the timing of changes and about future provision.
- agencies responsible for strategic planning should identify a lead person to ensure that there is coherent planning to meet the needs of young people with the most complex needs and to support maximum inclusion in mainstream services, using specialist services as appropriate.
- young people with learning disabilities should be able to access mental health services close to their home. Referral pathways must be clear and made known to young people and their carers.
- mainstream services should develop the resources and expertise necessary to respond to young people with learning disabilities, their families and networks

and should not exclude people because they have a learning disability.

- specialist learning disability services should be retained and developed both as a resource to mainstream mental health services and to support young people with the most complex needs.

The Count Us In Programme of Research

In order to develop the work of the Inquiry, the Foundation has funded four research projects aimed at improving access to high quality services. The two-year programme of research started during the autumn of 2002 with two projects based in Scotland and two in England.

A team from the University of Bradford is studying the needs of Pakistani and Bangladeshi young people with learning disabilities and mental health problems, where language and cultural differences make it harder to access services. Researchers from the University of Strathclyde are leading research into what young people with learning disabilities understand by anxiety and depression, its treatment and its impact on their lives.

A team from the Norah Fry research centre in Bristol is working with Somerset Joint Commissioning team and Connexions to identify and overcome barriers for those young people making the transition to adult services, and a team from the White Top Research Unit, University of Dundee are researching how mental health problems manifest in young people with profound and multiple learning disabilities.

The Well-Being Project

Professor James Hogg and Maureen Philip from the University of Dundee, whose research specialism is in service development for people with profound and multiple learning disabilities are undertaking this project.

Like all young people with learning disabilities, there is a growing awareness that young people with profound and multiple learning disabilities can also suffer from poor emotional well-being, becoming

depressed, anxious and stressed. However, because this group of people cannot talk about their difficulties, those who care for them may easily overlook their problems. The aim of this research project is to understand how family and professional carers identify changes in the mental well-being of young people with profound disabilities and the response they make.

The first phase of the research identified people with profound and multiple learning disabilities who experience mental health problems in two Scottish regions. While some families readily identified issues to do with emotional well-being, others reported that they had not considered before that their sons and daughters might have such difficulties because they were so often preoccupied looking after their physical health needs.

Seventeen interviews have been carried out with family carers and professional staff. The research team has started to review the detailed transcripts of the interviews and some of the early findings indicate that:

- a wide range of indicators of emotional well-being were reported, for example, changed communication and social behaviour, disruption of sleep and mealtime activities and challenging behaviour;
- parents reported that they had little confidence in professional advice when their son or daughter experienced difficulties in mental well-being and often sought their own solutions;
- parents/carers were able to identify a range of situations that affect mental health in adverse ways including bereavement, losing relationships, boredom and important transitions in life such as leaving school;
- the person's physical condition often affected mental well-being, whilst poor mental well-being could also lead to poor physical health;

- the well-being of the young person had a direct influence on the well-being of his or her parents;
- parents found different ways to support their children when mental well-being was poor, including the use of music, re-establishing routines and fighting for improvements to services.

The research team is now working with PAMIS (Promoting A More Inclusive Society), a national voluntary organisation, to produce a series of workshops for family and professional carers. Promoting working in partnership, parents participating in the research are actively involved in both planning and presentation of workshops. The aim of these workshops is to inform carers about the nature of mental health problems in people with profound disabilities and the strategies that may be used to help to identify and overcome such difficulties.

Summary

This article has summarized recent work on addressing the mental health needs of young people with learning disabilities conducted by the Foundation for People with Learning disabilities. Service provision is patchy throughout the UK and there is very little expertise or information available to parents and professionals caring for people with profound and multiple learning disabilities. The majority of assessments used in identifying mental health problems rely on people verbalising their feelings and experiences. These traditional approaches need to be adapted for use with the population of people with profound and multiple learning disabilities.

By interviewing families and professional carers of people who have experienced mental health problems the research project at the University of Dundee will provide us with a greater understanding of how mental health problems manifest in people with profound and multiple learning disabilities and ideas of how they can be helped to overcome them. The research project will be completed in late 2004 and we look

forward to reporting the findings in early 2005.

The Foundation has produced a number of booklets and reports in this area. One booklet, *All About Feeling Down* is for young people and draws on what young people with learning disabilities told the Inquiry. Another booklet targeted at parents, carers and teachers *Meeting the Emotional Needs of Young People with Learning Disabilities* gives advice both on how they can support young people to be emotionally strong and also cope with the difficulties they face at this time. There is also a full report, *Count Us In* price £27.50. All these can be obtained from the Foundation for People with Learning Disabilities 020 7802 0300 or at fpld@fpld.org.uk

The Foundation for People with Learning Disabilities is grateful to the Baily Thomas Charitable Fund for its support for the Inquiry and the research programme.

Jill Davies
Research Programme Manager
Foundation for People with Learning Disabilities
83 Victoria Street
London
SW1H 0HW
Email: jdavies@fpld.org.uk

Professor James Hogg
White Top Research Unit
Springfield House
15/16 Springfield
University of Dundee
Dundee DD1 4JE

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Please note

Rob Smith, whose article on developing ICT at Sunfield School appeared in the last issue of PMLD Link, recommended a software company called QOL. He has written to say that he has learned that the company has unexpectedly gone into liquidation and asked that this information be passed on to readers.

The Mental Health Needs of Young People with Profound and Multiple Learning Disabilities

In 2001, the Foundation for People with Learning Disabilities set up an Inquiry into meeting the mental health needs of young people with learning disabilities (Carpenter and Morgan, 2003). Its terms of reference were to:

- review and report on interventions to promote the emotional well-being of young people with learning disabilities;
- identify good practice and make recommendations for developments in policy and practice to promote the emotional well-being of young people with learning disabilities;
- review and report on services to meet the mental health needs of young people with learning disabilities;
- identify good practice and make recommendations for developments in policy and practice to meet the mental health needs of young people with learning disabilities.

Its findings and recommendations were incorporated in a report, *Count Us In* (2002).

The Inquiry conducted its deliberations, between October 2002 and July 2003, in various formats – committee meetings, focus groups, observations of interesting practice, consultation meetings. Written evidence was invited from parents, carers and professionals. Central to this whole process were two committee members, Emma Wilson and David Green, who themselves had learning disabilities, and personally conducted the focus groups with other young people with learning disabilities. The Inquiry Committee was trans-professional in composition with representatives from all four corners of the UK. The UK-wide brief for this Inquiry was one of its unique features, which has given it a significant relevance to each province in its dissemination phase.

Throughout the evidence gathering of the Committee a constant question formulated around the specific needs of young people with profound and multiple learning disabilities. Whilst the broad thrust of information, evidence, and exemplar practice had some relevance to young people with PMLD in the 13-25 age group (the age remit for the Inquiry), committee members were continually challenged by the lack of specific services available to them. Yet, there were many indicators to

suggest that particular patterns of provision would need to evolve if the complex range of needs exhibited by young people with PMLD, in relation to their mental health and emotional well-being, were to be met.

Implicitly, and ultimately explicitly, the Committee acknowledged that this issue was not going to be given sufficient space and depth in an already overcrowded Inquiry schedule. To try to subsume the specific needs of this student group in the overall outcomes, or indeed to discuss the evidence related to them, would have been irresponsible.

Subsequently the Foundation for People with Learning Disabilities has been able to fund a research project with a focus on the needs of young people with PMLD. Led by Professor James Hogg the study is entitled *What leads carers to identify changes in emotional and mental well-being in young people with profound and multiple learning disabilities and how do they respond?* The impetus for research around this question was recently summarised in a paper given by a parent, Jenny Whinnett (2004). She reported how following hospitalisation, due to pneumonia, her son Craig, a young man with PMLD, suffered depression. At first this was not recognised, but significant

sleep deprivation caused his mother to also suffer from depression. The recognition of these symptoms in herself led to her identifying the same mental health problem in her son. Medical intervention, through a baclofen implant, reduced his chronic spasms, improved his sleep pattern, alleviated his depression, and thus improved his mental health state.

This work, outlined in the previous article of this issue of PMLD Link, when finally reported, should be seen as complimentary to the main Inquiry report *Count Us In* (FPLD, 2002). The genesis of the questions posed by Professor Hogg's research project rest in the work of the Committee of Inquiry. The reported outcomes for the Committee report also form a context for this research. The outcomes of *Count Us In* have particular implications for all professionals working in the field of Profound and Multiple Learning Disability. There were 23 recommendations in all grouped around seven themes – Inclusion and Information; Promoting Positive Mental Health; Planning (of policies and services); In-house Structures; Service Network; and Workforce Development.

Readers are recommended to access the full report from the Foundation for People with Learning Disabilities (the addresses are listed on page 8) or read a summary on line (www.learningdisabilities.org.uk). For those working with this age group specifically in school or college settings, the discussion offered by Carpenter and Morgan (2003) may be helpful (See references).

The age focus for the Committee of Inquiry was 13-25 years, and as such schools and colleges are integral to supporting young people during their adolescence and into early adulthood. They have a specific role to play, firstly in acknowledging the vulnerability of young people and the risk to their mental health during this age period, and secondly that schools and colleges are therefore the first line response. They will see the indicators of mental ill health and the disintegration of a young person's emotional well-being. Schools and colleges should therefore ensure that there are

strategies for action within their pastoral system that will support young people during these times, and will know how to refer young people to other agencies should additional support be required.

Emerging themes for young people with PMLD

Throughout the Inquiry we constantly asked ourselves – “how do we keep our young people emotionally strong?” The pressures on them in modern society are enormous. This question was termed as ‘emotional resilience’. It resonates particularly strongly when considered in relation to young people with PMLD, for they are a genuinely voiceless population, often reliant on their own idiosyncratic forms of communication, or augmentative communication (e.g. objects of reference, picture exchange), or assistive technologies (e.g. voice output devices). How do they tell us of their depression, anxiety, fears or phobias? What have we provided within their chosen systems of communication that would enable them to do just that?

A telling piece of evidence to the Inquiry came from a mother, who told of the stress experienced by her daughter Marie, a young woman with PMLD. Having always been a happy child, with a well-developed range of vocalisation and gestures to indicate her needs, Marie, in adolescence became withdrawn and uncommunicative. At first her change in personality was attributed to the hormonal change that accompanies adolescence. However, when Marie's giggles and gleeful shouts turned to moans and wails her mother knew something more was afoot. Doctors had paid little or no attention to Marie's mother's descriptions of her changed emotional state, but when her weight began to decline dramatically then they reluctantly agreed to undertake some physical investigations.

These investigations showed that, in fact, Marie had a dislocated hip, and was in constant pain. The prolonged effect of this pain was to alter her mood, quite simply from happy to sad. With treatment the pain was reduced, and Marie not only gained

weight, but her previous pleasant disposition returned.

This example directly illustrates how physical state can impact upon emotional well-being. There are real challenges to professionals, particularly those concerned with communication development, to consider how we facilitate expression of emotions for young people with PMLD. We have to find ways of ensuring that the emotional context for their personal and learning development remains strong.

Many writers (Lacey and Ouvry, 1998; Ware, 2003) have indicated that the holistic development of the young person with PMLD is of paramount importance. Yet curriculum developments in recent years have often ignored the emotional/affective dimensions in that developmental profile. Perhaps it is the intangible nature of emotion (or its deeply personal roots) that causes us to do little more than acknowledge its importance? The raised profile of Personal, Social and Health Education and Citizenship in the curriculum, may give us channels through which self-esteem, self-awareness and self-advocacy can be nurtured. Lawson and Fergusson (2001) describe how positive self image can be taught through young people learning about themselves, their appearance, abilities, strengths and weaknesses, likes and dislikes, own feelings and personal qualities.

What is the imperative for us to do this? Valerie Sinason, a Psychotherapist, has written extensively in the area of self-esteem and personal development (c.f. Hollins and Sinason, 2000). She gave evidence to the Inquiry which really challenged committee members. She asked 'What is it like to wake up every day with a physical, intellectual and sensory impairment?'. Over time how does this life-disorientating combination of disabilities impact on the emotional state of the young person with PMLD? We cannot truly answer for our young people with PMLD, but we can resolve to 'listen' to their emotions. The sensitivities of parents, carers and professionals working on a daily

basis with the young person, will attune to their emotional state: a dialogue around these emotions can be fostered by reflecting back to the young person. Simple turn-taking, interactive games exploring emotional literacy can be triggers to deepening our understanding of the emotional experiences of the young person. Which objects or pictures can form cues and reference points to ensure that a repertoire of emotions is established? Scripts based on 2D/3D clues may enable the young person with PMLD to explore social situations, and practise/rehearse the emotions and social responses specific to these contexts. Through the 'scripting' of a situation young people can enhance their social understanding and clarify what is expected of them, and other participants, in a social situation. As such it teaches coping strategies and can incorporate activities to minimise anxiety and develop appropriate communication strategies. It is important that young people with PMLD know what supports are available to them, and how and when to use them.

Emotional difficulties are particularly common in adolescence, and the anxiety, depression, phobias and behaviour difficulties may be features of this time of life (Emerson, 2002). This Inquiry has highlighted how a failure to meet their mental health needs particularly affects the lives of young people with special educational needs and learning disabilities. Indeed for young people with PMLD this failure can close the windows of emotional dialogue, with life-devastating consequences. The Inquiry report asserted the right of all young people with learning disabilities to positive mental health and emotional wellbeing. Ongoing research is seeking to indicate how this may be particularly achieved for those with PMLD. But it is more than one research project; it is the shared, corporate responsibility of all families and professionals alike – to ensure that this group of young people is not marginalised further because we fail to give due recognition to their emotional state. I am reminded of Pat Fitton's (1994) powerful description of the emotional journey throughout the life of her daughter, Kathy,

(who had Profound and Multiple Learning Disabilities). Kathy laughed at life, she grumbled at life, she shouted, cried and screamed at life; but always she remained, through her emotional expressions so powerfully communicated, in dialogue with life. Is that so for all of our young people with PMLD? And if it is not, what can we do to enrich their emotional discourse and restore their emotional resilience?

Professor Barry Carpenter,
Chief Executive,
Sunfield School,
and Chair of the Inquiry into the Mental
Health Needs of Young People with
Learning Disabilities
Email: barryc@sunfield.worcs.sch.uk

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When Feeding Becomes Technical: Using PEGs

The first time I heard of a PEG was in 1991 when my nephew, James, needed one. I was a nurse for people with learning disabilities but I had never been involved in caring for someone whose food and drink was given in this way. My sister, Karen, and her family had lots to consider when making the decisions about James's nourishment and it seemed scary. However, with two of her other children now with PEGs I consider her to be an expert in using, troubleshooting and understanding the risks and benefits of PEG feeding, hence we are writing this together.

What?

PEG stands for Percutaneous Endoscopic Tube. It is a tube placed in a hole (stoma) through the abdomen wall into the stomach (gastrostomy) or into the small intestines (jejunostomy). This is a surgical procedure; the tube is held in place so it does not fall out and liquid feed is put through the tube into the person's stomach or small intestines. James, and the other children, also had a Nissen Fundoplication performed at the same time (an operation on their stomach) because they had severe reflux resulting in vomiting and repeated chest infections.

Why?

People need PEGs because they cannot eat and drink enough, resulting in malnourishment (Pennington 2002). Before a doctor recommends a PEG you know there are problems with eating or drinking and you may have tried different ways to help the person. For example, different texture food, drink thickeners, change of feeding positions, and using a tube that goes up the nose and into the stomach (nasal-gastric). The person you care for will have had medical tests to identify the problems and to examine his or her swallowing. If the ways explored are not successful or it seems that tube feeding will be a long-term way to help the child to get enough food and drink, then doctors may recommend a PEG as they are better tolerated long-term than the use of nasal-gastric tubes.

Is it really needed?

We were unsure that we were making the best decision for James, and so we looked for information to help us. Our advice is ask for all the information possible to help you decide if having a PEG inserted is the best decision. Ask why a PEG is needed, ask about tests and get results explained in ways you understand. We were told that James could not swallow safely anymore. More food came out of his mouth than went into him, and his malnourishment and dehydration effected every part of his life. Ask about any risks, but also ask about any benefits. We were told that James would get his medication through his tube and consequently his seizures would be better controlled. We were also told he would gain weight. We found that being told about caring for the stoma both before the insertion is made, and immediately afterwards, together with advice on the use of the PEG was essential, but we wished we had known more about the feeds, tubes and pumps that are used.

We also needed to know more about the implications for James's medication, and it is also important to discuss the realities of PEG feeding with carers who support a person who has one. Naturally, a doctor can give medical and technical information but he or she does not understand the problems of PEGs at school! Nor does he or she understand the feelings that carers have if they cannot give someone a piece of birthday cake or ice-cream when other children are allowed them. Doctors can *talk* about the guilt you feel about not feeding, but they cannot know just how bad it feels.

Coming to terms with not feeding someone you love takes time and needs empathy from professionals. Feelings of guilt are strong when you are sitting enjoying your own meal and not feeding someone else, and are hard to discuss. Food is part of our culture and many festivals have related foods and drink. How other children in the family can be involved in PEG feeding may also be something that you may want to talk about. Eating is a social occasion that many children like to be involved in.

Another aspect for consideration before the PEG is fitted is what to do if the tube comes out. The first time this happened to James we were rushed to Great Ormond Street, a two-hour journey there and back to home. Luckily help has improved in our area, and we have local support with the other two children, but we have now been taught how to replace the tube ourselves.

What risks?

Research has been carried out that indicates that the use of PEGs does not prevent aspiration pneumonia (Finucane, Bynum and Julie, 1996) and can make the condition worse. If your doctor is recommending a PEG because of aspiration of food, ask about current research and what the results show for your own situation. It may be that it is, indeed, the best thing for the person you care for, but check it out.

There are, of course, problems with PEG feeding in schools. Other children can pull at the tubes especially if feeding continues throughout the school day. The most distressing thing for our own children was to be made to go into the dining room at lunchtime and watch everyone else eat. This was intolerable, and led to 'challenging behaviour' at mealtimes. The children acquired an additional label they did not deserve.

Respite was an issue although owing to the rise in the number of children who have PEGs things are improving. If you use another family as shared carers, check they will be allowed to give the feeds which are

considered to be medical procedures. Mouth care can also be a problem.

What Benefits?

Research carried out by Marin in 1994 and Sulaeman in 1998 demonstrated that PEGs were safe and effective for children except those with multiple-system organ failure. All the children we have cared for have benefited from having a PEG. They gradually gain weight and grow, their malnutrition and dehydration problems go, other medical problems such as diabetes and epilepsy are easier to control and with more stable health they can experience lots of activities, making their lives more stimulating and enjoyable. Our own children concentrated better and got cheekier! Meal times are no longer stressful and if, for example, Perry wants something to eat then as long as he is with his mother whilst he has food in his mouth, he can have a small amount.

In using PEGs we do not have to deal with choking on food, nor tolerate long mealtimes, cold food, suction machines, or seizures and, most importantly, we do not have to worry that the boys are not eating enough.

What will happen when a PEG is fitted?

Normally a person goes into hospital for the PEG to be fitted. He or she will stay until the body is absorbing the feed, and a feed regime is set up. Feeds are given in two ways, either by gravity through a syringe (no needles) or by a pump. Feeds can be given in small quantities over many hours, or in larger amounts intermittently throughout the day. If a feed is given over a long periods you should have a portable pump so the person's life is not restricted. Feeds and tubes, called 'giving sets', are usually delivered to your home and you are given an emergency number in case the equipment goes wrong or you need advice.

You are taught to care for the stoma and the tube, how to set up, give the feed and any medication, and how to reduce the possibility of infection. You will also be taught how to solve minor problems; our usual mistake is to forget to release the clip

on the tube that stops the feed dripping out when you are getting it ready, which causes the pump to bleep when it is turned on.

Our life now

James, unfortunately, died 5 years after he had the PEG fitted, but he would never have lived that long had he not had the PEG and it certainly improved his quality of life. The other two children are doing well with their PEGs, but the Nissen Fundoplication did not work for one of the two, and he still has reflux and vomiting. It did, however, work well for the other and we just keep an eye on him in-case he wants to vomit and can't. If this happens we let the vomit come out of his tube. Due to the PEGs they have gained weight, they do not get dehydrated and when they are unwell we can maintain their feed, fluids and medication. Their skin is better and pressure sores are very much fewer. We know how well all this has worked because they are back in full time education (not that they are impressed!) and are getting on with 'being boys'.

After thirteen years of managing PEGs it can still be hard; especially when eating out with the family. People see that the boys are sitting to one side 'being starved by their

selfish parents'. They can be very judgemental and I sometimes want to scream.

Help

Today help can be obtained from a number of sources. Leaflets are available on the fitting procedure of the PEG, on care of the stoma, and on the special diets. Contact sheets can be obtained from the community nursing team which give information on support groups; where to order feeds and tubes; and who to contact in an emergency. In a study reported in 2002 Pennington found that PEGs usually last for 2-3 years before they need to be replaced (as long as they do not get pulled out or blocked), although, in our case, it is necessary to change the 'Mic-key' button that the boys have every 6-8 months and it is possible to do this ourselves.

Kim Scarborough is a Senior Lecturer at the University of the West of England

Karen Harman-Page is the parent of 6 children, 3 of whom have had PEGs

Kim Scarborough can be contacted by e-mail Kim.Scarborough@uwe.ac.uk

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Sulaeman, E. et al (1998) 'Gastroesophageal Reflux and Nissen Fundoplication Following PEG in Children', *Journal of Paediatric Gastroenterology and Nutrition* 26 (3) pp 269-273.

For more information:

Merck Pharmaceuticals 01895 452258 provide some good leaflets including one called *My Secret P.E.G* (a great publication for children).

<http://www.bris.ac.uk/Depts/NorahFry/food/thinking.html>

WHAT ABOUT THE CARERS?

The term 'well-being' is very much an 'in phrase' at the moment and is often accompanied by two further words 'in the work place'. Recently, councils up and down the country have been busy publishing strategies to ensure that 'well-being in the work place' is being addressed for all employees.

The results of research revealing the impact of the 'workplace' upon our health and well-being are being taken seriously. The cost of ill health and the time off taken by employees has prompted the implementation of policies to ensure that the 'work place' supports those in employment, and does not contribute to a rise in work-related stress conditions resulting in ill health. Fine, if you work in the public sector!

Initiatives to ensure well-being in the work place are to be commended, but one group of people is being seriously neglected: the carers. The well-being of all people with going to have a considerable impact on the health of the carer who may experience physical difficulties, fatigue and/or exhaustion. In contrast, employees suffering from work related stress are able to take time off from the pressures if supported by a doctor's certificate. If, however, a carer is unwell, he or she still needs to continue to look after his or her son or daughter and the 'job' of caring does not end at 6 p.m.; it continues for 24 hours, seven days a week.

I am painting a depressing picture but recent research, conducted by Mencap, supports what I am saying:

'I go to bed and cry my eyes out, hoping it will be better in the morning'.

(Renee, a parent and carer who took part in Mencap's *Breaking Point* survey)

Just over two years ago, Mencap's survey *No Ordinary Life* (published in November 2001) considered in detail the support needs of families caring for children and adults with profound and multiple learning

PMLD, who live at home, is underpinned entirely by the well-being of their carers. It is this aspect of well-being that I want to focus upon and to share some ideas which helped me when caring for our daughter at home.

Doctors now understand more fully the impact of stress on our general health and there is a strong emphasis on preventative strategies rather than reactive medicine. Although there is now widespread recognition of the needs of carers to ongoing support, little has been done to help them. Caring for someone over many years for a minimum of eighteen hours a day is obviously a considerable burden. It was found that 60% of parents spent more than ten hours a day on the basic physical care of their offspring and 57% also spent more than eight hours a day on therapeutic or educational activities.

The *Carers (Recognition and Services) Act 1995*, highlights the rights of carers. It makes it clear that carers providing a 'substantial amount of care to someone on a regular basis' have the right to an assessment of their needs alongside the assessment of needs of the service user. This assessment is the key to receiving any support from social services. The provision of a short-term break is not a legal right, and has to be identified as a 'need' when the assessment is carried out and detailed in a carer's care plan. Unfortunately, there are huge regional variations in the actual support that carers receive and, sadly, in some areas where access to short term breaks has been identified in the care plan, there is no guarantee of the service as it is dependent upon available resources.

Mencap has recently launched the campaign *Breaking Point* which depended on the survey of the same name. The

survey was carried out in the Spring of last year and seventy six families from across the UK and Northern Ireland took part. For more information, and to read the report in full log on to www.mencap.org.uk/breakingpoint

Suggestions are made of ways in which you can support the campaign, and help to raise the profile of the needs of carers. As part of the survey 325 members of the public were interviewed and it was revealed that:

- 99% of members of the general public agreed that carers need a break;
- 76% thought carers were woken on average three times a night – (correct!)
- 84% thought that carers spent an average of 18 hours a day looking after their son or daughter with a disability (correct!).

The title of the survey is *Breaking Point*, a state that no carer would want to reach, but every day many are finding the pressures too much. Carers, in my experience, are incredibly resilient people but I admit that I was always terrified of not being able to cope. For me it would have been an admission of failure; what sort of mother was I if I couldn't even care for my own family? In such a situation it is one of the most difficult things in the world to be able to ask for support. I used to find it difficult to know if I *should* be asking for help: my dilemma was a bit like phoning the doctor's surgery to ask for an appointment and the receptionist replies 'I'm afraid we have no appointments for any of the doctors until next Thursday, but if its an emergency you can come to our emergency surgery after 6 tonight.' We tend to think of *emergency* needs as life or death and therefore will wait for the next available appointment with the doctor. If you are a carer and feeling at the end of your tether, its still difficult to bring yourself to acknowledge that you have reached 'breaking point' and need help now, not next week.

Carers are not quitters and they can at least receive some comfort from the fact that their

support needs are now featuring in many of the strategic planning documents of councils up and down the country. The seven county council websites that I logged onto in the course of writing this article, have detailed plans and charters for carers. Ensuring that these plans and charters are put into *practice* is the challenge!

Some tips for well-being

- Do ask your social services to carry out an assessment of your needs and to draw up a care plan.
- Register with your local carers' association. It should be able to offer lots of information, support and advice, and often has a free help-line.
- Do visit your GP and ask for his support in your caring role. Many GPs are willing to help a great deal to ensure that you get access to the support services you and your family need.
- Do enlist the support of a friend who would be able to act as an advocate on your behalf, and offer moral support when things are very difficult for you.
- Try to make time for yourself; it is tempting to rush round doing all the extra jobs at home when there are a couple of hours spare, but learn to be a bit selfish and go for a swim or a walk, take up a hobby (such as music or painting), join a yoga/pilates class, shop, have that long hot bath with aromatherapy oils!

For more information on support, help and advice for carers, the national website is, www.carersinformation.org.uk

Julia Dixon
Parent, and Early Years Advisor. The Lodge, Willow Bank
Somersal Herbent, Nr Ashbourne,
Derbyshire DE6 5PD
Email: Julia@Dixon2.demon.co.uk

Don't Mention It!

It disrupts lives, limits opportunities, constrains family activities and can increase

'You probably don't live the life that you should be living. The young person isn't being allowed the variety of outings that they would be given under different circumstances. That is a big problem for you, because you think is it worth putting myself through it? Is it worth putting my daughter through it? And again, you're always having to deal with the public's attitudes.'

The issue I'm referring to is incontinence. For the last few months I've been working with a group of people with learning disabilities, family carers, support staff and managers on the production of a training pack about the management of continence, commissioned by the British Institute of Learning Disabilities (BILD). The project focuses on adolescents and adults, rather than children, mainly because the issues are different, although there is some overlap. It encompasses all degrees of learning disability.

Because of the social stigma associated with incontinence there is a great deal of public ignorance and misinformation. Over recent years, campaigning and support organisations such as 'Incontact', 'PromoCon' and the 'Enuresis Resource and Information Centre' (ERIC) have promoted awareness of the extent of the problem and better ways of responding to it. The UK government, as well as health and continence specialists, have published a number of documents which advocate an inclusive and integrated approach to continence care and provide best practice guidelines (DOH, 2000; NHS, 2001; NHS Scotland, 2002; Thomas, 2000; Rigby, 2001; Bayliss et al, 2003). But it's a long road from inclusive policy to implementation at service and individual level, especially when it concerns people with learning disabilities.

Even in these days when there is growing acknowledgement of the health inequalities they encounter, continence remains a

dependency. A considerable number of people with profound and multiple learning disabilities are affected by it. One mother of a teenage daughter told me:

neglected area of research and support. In common with what other writers found, (Huntley and Smith, 1999; Grieve, 1998; Radford and Anderson, 2003;) I discovered only a handful of current articles dealing specifically with adults with learning disabilities amongst thousands on adult continence in general. The common assumption is that any incontinence is inevitably the result of the learning disability. (Hyams et al, 1992; Hutchinson, 1998). True, the more severe the disability, the more likely it is that the person will have difficulty with continence, but the exact link between intellectual impairment and incontinence is not clear. Although profound learning disability is likely to be a contributory factor for some people, other variables are too often overlooked: the effects of limited mobility; communication difficulties (of both staff and service users); lack of opportunities for learning and the low expectations of other people, for example.

What is certain is that continence management is an area that has particular significance for workers supporting people with profound and multiple learning disabilities. The automatic response of medical professionals is to provide pads, rather than to investigate cause and consider other options, as one mother's experience demonstrates:

'Of all the time I've dealt with the incontinence department as a parent there was never any help offered on how I should be achieving A's toilet training. Their main thing was just to give me products.'

Hutchinson (1998) writes of a woman with profound and multiple learning disabilities assessed by a district nurse as having a mixture of stress and 'urge' incontinence. Instead of being offered the treatment options which would be made available to non-disabled women, she was automatically given incontinence pads. When this decision was challenged, the woman received

electrotherapy and medication, which resolved her continence problem and saved her wearing pads for the rest of her life.

There is, of course, much more to continence management than being able to use a toilet, independently or with assistance, important though this might be. The emphasis in this project is on the *self* management of continence: empowerment for individuals through improved communication, active support and increased control over their own lives. For one person this might mean treatment and subsequent cure, while for another, it will be more effective continence products that improve comfort and quality of life. For the substantial number of people with profound and multiple learning disabilities who do not attain continence, good continence management is still entirely relevant. Such management means ensuring that each person receives the most appropriate support possible by working in partnership with families and includes identifying and dealing with any underlying physical causes, keeping up to date with developments in continence products, as well as adopting a holistic approach to promoting health and well-being.

The BILD managing continence project is in its mid-stages, but certain issues are emerging that are particularly relevant for services and staff supporting people with profound and multiple learning disabilities. Firstly, there is the importance of openness in discussing this important area of work, which takes up a considerable amount of time, but is seldom recognised officially. Continence management, alongside other intimate care tasks, is very much the 'hidden' aspect of support work, yet it is fundamental to well-being. Rather than seeing it as a time for positive interaction, better communication and an opportunity for choice and decision making, there is a tendency for workers to adopt a 'get it over with and don't talk about it' approach. One person I interviewed said:

'If you talk to people while you are doing things, it makes it all the easier, but certainly avoid talking about what you are actually doing, except to check – I'm

not hurting you, is this uncomfortable, is it too hot, too cold – I try to take their mind away from it, make it easier.'

Although well meaning, this reinforces the notion that intimate care is a low status, distasteful aspect of work that shouldn't be mentioned; an attitude that is easily conveyed to service users and which further devalues the role of the support worker. Cambridge and Carnaby (2000) make reference to the 'running commentary approach' (p.50) (which some workers equate with involvement) but which is almost entirely informative and involves complex language that is difficult for service users to understand. Such an approach leaves them no time to respond, never mind becoming actively involved.

Undoubtedly, some aspects of continence support, such as dealing with bodily waste, are difficult, but there are other tasks that provide opportunity for positive interaction and the best possible care. Another support worker explained her approach:

'I'm just a great advocate for intimate care, that we go that extra mile to make sure it's done right. ... L. needs complete, full support in the bath, but when she comes out of the bath, she will need to be dried and pads put on, is what's required. But I don't – I get body spray, and talcum powder so her legs don't get chapped – all these things. I just think to try and make it as comfortable as possible. I show them to her and ask her what ones she wants. We both enjoy this time together.'

There is also a need for more appropriate training in relation to continence management. Carnaby and Cambridge (2002) in their study of intimate care, found that workers require much more specific guidance than is generally provided by organisations. This is borne out by my discussions with carers, although it varies from service to service, with some organisations providing ongoing training and others relying on workers to develop their own practice according to instinct. As most workers are women it is assumed that caring is an automatic aspect of women's work.

Emphasis in training is often on technical advice, issues relating to health and safety and generic notions such as treating people with dignity and respect, without guidance on how all this can be translated into practice. Value based training is important, as is skills training, but people need to be taught how to combine these and develop sensitive competence.

Communication is particularly important. The use of signing, pictures, symbols and objects of reference, for example, are as relevant here as they are in other areas of a person's life. An atmosphere conducive to interaction is essential, where the person feels relaxed and important. There is a prime opportunity for workers to develop their own knowledge of a service user's ways of communicating – signalling discomfort, expressing choice, and initiating interaction, for instance. All this requires ongoing training and management support, not just a brief mention at induction.

Continence management needs to figure *explicitly* in policy and procedural documents and the *Essence of Care* benchmarks provide a good starting point. Developed by the NHS in 2001, these benchmarks are divided into a number of areas which apply to people with learning disabilities, as much as with anyone else. Within policy documentation and procedural guidelines, more challenging issues such as: sexual arousal and sexual harassment; physical and sexual abuse during continence care; challenging behaviours such as smearing faeces or physical assault; and the potential difficulties for gay and lesbian staff or service users of same sex support, are often dealt with unsatisfactorily or not at all.

Cambridge and Carnaby (2000), in their training pack, *Making It Personal: Providing intimate and personal care for people with learning disabilities*, include line drawings which provide a basis for staff discussions on these difficult but real life issues. Managers need to allocate time to such activities and need to be ready to seek help from appropriate professionals before

events get to crisis point and problems become more ingrained.

Another critical issue involves understanding the implications of different cultural norms and requirements on continence management, reflecting them in policy and applying them in practice. Maudslay et al (2003) highlight the importance of actively recruiting and training workers of both sexes from minority ethnic communities and making sure that policy directives are inclusive. Continence management also requires inter-professional collaboration and partnership with families, just like other support work. One mother highlighted the importance of professionals learning to listen to parents, but said that parents too need to listen to professionals:

'We do enclose parts of our own lives. We do live in this wee world that all revolves around our routines, and sometimes our routines aren't necessarily good routines, and if someone suggests that we change them, we should think about it and – it may not work, and it may not be acceptable, but just to be open.'

The PAMIS (Profound and Multiple Impairment Service) initiative, *Changing Places, Accessible Toilets for All*, which campaigns to ensure that toilets for disabled people become fully accessible by including a height adjustable changing bench and more space for non-standard wheelchairs and for helpers, is a prime example of collaboration between parents and professionals from a number of organisations.

Accessible information is an important part of good continence management for staff, family carers, managers and people with learning disabilities. One of the main reasons BILD embarked on this project is because of the dearth of appropriate information on the subject of continence for people with learning disabilities. Organisations such as 'ERIC', 'PromoCon' and 'Incontact' produce information for all of these groups. Services and schools will find the pack by Cambridge and Carnaby, mentioned on the previous page, a particularly useful resource for staff, parents and other professionals. Adult services and schools have an important role as

advocates for people with learning disabilities and as educators of mainstream professionals such as doctors and nurses. The publications *Once a Day* (NHS, 1999) and *Signposts for Success* (NHS, 1998), while not dealing specifically with continence, provide useful guidance on general health services for people with learning disabilities and are well worth reading in this context.

Another urgent need is the dissemination of information about good continence management in practice. There are likely to be many examples of innovative practice we never get to hear about because their instigators don't realise just how valuable this information could be to colleagues further afield, or perhaps because of constraints of time and other commitments. If you have good ideas, approaches and resources that work well and you would be willing to share them, I'd love to hear from you and will include these in the publications where possible.

The BILD pack on the management of continence will be published in the Autumn of 2004, and will comprise three books:

- an easy-read book for service users (part of the *Your Good Health* series),
- a staff workbook linked to the 'Learning Disabilities Awards Framework' (LDAF: www.ldaf.org.uk)
- a manager's Reader.

The entire project has been made possible through a grant from the Department of Health.

Alice Bradley
Freelance worker (Training and Development)
Email: abradley@scot1.freemove.co.uk

More information on the pack can be obtained from:
BILD, Campion House,
Green Street,
Kidderminster,
Worcs, DY10 1JL.
Tel: 01562 723010.

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Useful Organisations

- Incontact www.incontact.org
- Promocon www.promocon2001.co.uk

Enuresis Resource & Information Centre www.eric.org.uk

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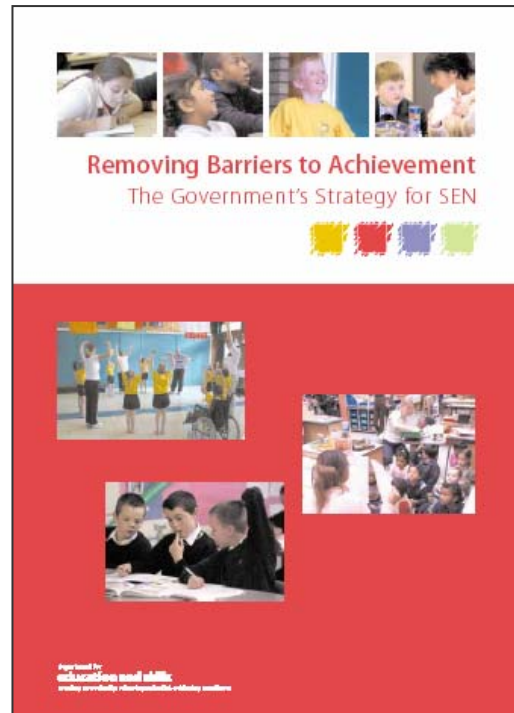
Removing Barriers to Achievement. A new Strategy for Special Educational Needs and Challenges and Opportunities for Children and Young People with PMLD

Introduction

Removing Barriers to Achievement is the Government's new long-term strategy to transform the education of children with special educational needs.

The SEN Strategy has six over-arching objectives, namely:

- a strong focus on early intervention;
- developing personalised learning for all children, making education services more responsive to the needs of individual children;
- removing the barriers to learning that can prevent children with SEN, with a sharper focus on children's progress;
- educating children with SEN in mainstream schools, supported by special schools, which will become centres of excellence;
- a clear and continuing role for special schools which involves educating children with the most severe and complex needs and working closely with mainstream schools to share expertise and extend learning opportunities for all children;
- developing closer partnerships between education, health and social services, the voluntary sector and parents.



Importantly for children with PMLD, the Strategy must be read in the wider context of other Government initiatives. Charles Clarke, launching the SEN Strategy on February 11th, noted that:

'The reform of children's services set out by our Green Paper, *Every Child Matters*' with its focus on early intervention, preventative work and integrated services, will deliver real and lasting benefits to children with SEN and their families. *Removing Barriers to Achievement* sets out a long-term programme of change through partnership working with local authorities, schools, early years settings, health and voluntary sectors to improve provision for children with SEN. Its implementation will be part of the wider development in children's services flowing from *Every Child Matters*'.

Mainstreaming SEN within the broader range of health and social services is of course particularly important for children with PMLD.

Meeting the challenge

There is much to welcome within the SEN Strategy. Firstly, there is a focus on achievement and progression for all children. Secondly, there is a shift in emphasis towards making changes to improve the environment within which children learn and thereby to 'whole school policies' to support personalised learning. Thirdly, as noted above, this is the *Government's* strategy and not a matter for the DfES and SEN services alone. In effect, there is an acknowledgement that the problems in creating effective and appropriate packages of support for SEN have frequently related to *non-educational* providers and a lack of 'joined-up' planning and delivery of services. Hence special educational needs are now everybody's business!

The Strategy sets out a major agenda of change. The Audit Commission (2003), noted a number of continuing challenges in the improvement of SEN services, namely:

- notwithstanding recognition of the importance of early intervention, too many children wait too long for appropriate support;
- some children who could be taught in mainstream settings are not offered the opportunity because of anxieties about capacity and teachers' anxieties about their ability to meet their needs;
- many special schools feel uncertain of their future role, at a time when there is growing recognition of the increasing complexity of some children's disabilities;
- many parents are anxious and confused by the complexity of assessments. Cases to the SEN and Disability Tribunal have increased by 16 per cent in 12 months and reflect continuing concerns about access and entitlement to services.

The SEN Strategy proposes to address these anomalies by:

- *Early intervention* – with children receiving appropriate early support and parents having access to suitable childcare. Currently only 32% of mothers of disabled children are employed, compared to 89% of mothers with non-disabled children.
- *Removing barriers to learning* – by embedding inclusive practice in every school and early years setting.
- *Raising expectations and achievement* – by developing teachers' skills for meeting the needs of children with SEN and moving beyond performance tables to focus on the progress which *individual* children make.
- *Working in partnership* – the Strategy encourages partnerships between mainstream and special schools; between schools and community services; between health, education and social services and, of course, active and positive partnership with parents.

Moving the Strategy's key themes forward: Early Intervention

Early intervention is the cornerstone of the Strategy. Families (and schools) often face unacceptable variations in the level of support available from schools, local authority and child health services.

The Strategy proposes:

- a feasibility study for a National Centre of Excellence in Early Intervention, in order to establish a sound evidence base for early intervention and education and to support research, development and professional development in this area;
- a new strategy for childcare for children with disabilities or SEN, which will integrate early education and childcare and improve information for parents;
- encouragement for local authorities to extend SEN advice and support services to early years settings;
- ensuring that guidance for working with young disabled children and families in *Together from the Start* and the related Early Support Pilot Programme inform the future development of services for this age group. This has considerable implications for young children with PMLD because of the proposed introduction of the role of the Keyworker and the Family Service Plan.
- further delegation of funds to schools to support early intervention

Improving Inclusion (and redefining the role of special schools and services)

The SEN Strategy reaffirms the Government's commitment to further developing the inclusion agenda, proposing a new Inclusion Development Programme. However, it also clearly states that inclusion is much more than the type of school which a child attends. Section 2.12 states that:

'some special schools have felt threatened by the inclusion agenda and unsure about what role they should play in future. We believe that special schools have an important role to play within the overall spectrum of provision for children with SEN – educating some children directly and sharing their expertise with mainstream schools to support greater inclusion.'

The SEN Strategy proposed that:

- special and mainstream schools will become part of a '*wider community of schools*', within a unified system which will see greater staff movement and pupil movement between sectors. Schools now have scope (under the Budget Shares Regulations) to use their budgets flexibly for the benefit of pupils registered at other maintained schools and we are likely to see increasing recognition of special school outreach to complement existing advice and support services.
- special schools (including those in the non-maintained and independent sector) should participate in federation, cluster and twinning arrangements with their mainstream counterparts: an exciting opportunity.
- collaboration can bring real benefits to both sectors and some new 'communities' of schools are already emerging (for example Beaumont Hill Technology College, described in section 2.13). The DfES's capital funding strategy, including the *Building Schools for the Future* programme, offers real opportunities for a range of new partnerships, ranging from co-location to outreach, training and other activities (including after-school and holiday activities through the Extended Schools Programme).

Educating children with the most severe and complex needs (section 2.14)

The SEN Strategy acknowledges the challenge of meeting the needs of a growing number of children with very complex needs. It proposes (2.15) a strategic role for local authorities in planning a spectrum of provision to meet these children's needs. Such planning should acknowledge that the proportion of children educated in special schools should fall over time as mainstream skills and capacity improve – but a small number of children are likely to continue to need special provision.

Whilst envisaging a continuing role for special schools, the SEN Strategy also acknowledges the need for improvement in the special school sector. Special schools are three times more likely than mainstream schools to be on special measures and a range of preventative strategies are proposed, including: promoting leadership and management training for special school heads and managers; promoting mainstream/special school collaboration to support school improvement; and the development of tools to enable local authorities to identify potentially failing schools.

The Strategy addresses the issue of children with low incidence disabilities and SEN attending residential schools (2.29). There are around 6,200 pupils in maintained and non-maintained residential special schools in England, with a further 2,800 in independent residential special schools. The majority have significant multiple health, social care and educational needs.

The costs of residential placements are considerable and the Strategy proposes to work with local authorities and SEN Regional Partnerships to promote effective regional and sub-regional planning to make appropriate provision for children with low incidence SEN. It is hoped that there may be more joint investment by local authorities and other agencies in the development

of local provision. The DfES proposes to pump-prime the creation of regional centres of expertise, providing specialist advice, training and consultancy support to staff in mainstream settings. Such regional centres could be based in special schools and link into wider aspirations to create more joint working between the mainstream and special school sectors.

Raising expectations and achievement

The Strategy rightly acknowledges that:

'we still do not know enough about the progress made by children working below age-related expectations, around 50% of whom are not entered for national tests and examinations beyond KSI.'

Therefore, the PMLD readership will warmly welcome the focus on personalised learning (3.1) and proposals to promote and extend the use of P Scales (3.20) to measure the progress made by those pupils working below Level 1 and to collect this data from 2005.

Similarly there are proposals to consult on changes to the Performance Tables so that schools at last get real credit for the achievements. The PMLD readership will warmly welcome the focus on personalised learning (3.1) and proposals to promote and extend the use of P Scales (3.20) to measure the progress made by those pupils working below Level 1 and to collect this data from 2005.

Planning for the future –making transition work

Making the transition beyond compulsory education can be particularly challenging for young people with learning difficulties and complex needs. There is extensive guidance around transition and the Connexions Service can work up to age 25 for this group of young people. However, the Strategy acknowledges that local arrangements are often fragmented and confusing. New national standards are proposed to support a smooth transition from children's to adult services, building on the National Service Framework.

There is an ongoing agenda around transition for young people with PMLD. The Strategy's proposal for stronger partnerships with local Learning Disability Partnership Boards is welcome. The Boards, established in response to *Valuing People*, the Government's Learning Disability Strategy, bring together local partners from health, education, social services and the voluntary sector. Many include people with high support needs within their local strategic planning.

Every Partnership Boards is required to have a 'Transition Champion' to encourage better joined-up planning. But real dialogues with children's services about the 'next generation' coming into adult services are still variable. Perhaps I can pose a personal challenge to readers and ask that you make contact with your local Partnership Board and make sure the needs and expectations of the current young population with PMLD are fully recognised.

Delivering services in partnership

As noted above, the SEN Strategy needs to be read in the broader context of other major Government initiatives to transform children's services, such as *Every Child Matters* and the *National Standards Framework*. A key theme in all three documents is that of partnership – between schools and LEAs; between education, health and social services and at regional level. The SEN Regional Partnerships will have a stronger role in implementing the strategy. And a new team of 'expert advisers' will provide '**support and challenge on key SEN issues**'. The SEN Strategy will build on the proposals for integrating children's services in *Every Child Matters*, in particular the common assessment framework and Children's Trusts, to deliver joined up services for children and families.

Improving specialist advice and support for schools

Research commissioned by DfES and NASEN (2.35) suggest that increased delegation of SEN resources has eroded the availability of support in some areas. The Strategy envisages further delegation *'but not at the cost of SEN support services'*. Therefore it is proposed that generic minimum standards for SEN support services will be introduced - to be used for self-evaluation by local authorities and in OFSTED inspections. One objective for the standards will be to *'make the best use of existing specialist provision including special schools and specialist resource bases and units in mainstream schools.'* For children with low incidence disabilities and complex support needs, the proposed standards offer both an opportunity and a challenge – and a task for all those involved in working with children and young people with PMLD.

Partnership with parents

An over-arching theme in the SEN Strategy and related initiatives is that of partnership with parents. Over the past few years, there has been a range of positive initiatives to support families. Parent Partnership Services have developed capacity and many LEAs now have Parent Forums – a move from individual parent involvement to partnership in wider policy making. However, improving accountability and transparency (particularly around funding) to parents remains a challenge

In conclusion

Removing the Barriers to Achievement is a long-term strategy and all the more welcome for it. Many of the proposals within the Strategy will require development, evaluated implementation and careful thought about future sustainability. The Strategy addresses the challenges (and opportunities) within the inclusion agenda and the potential tension of an increasingly complex population of children with complex disabilities. And, importantly, it focuses on all children's *potential* for achievement and right to education. It is honest about how much we need to learn and do in order to achieve its recommendations – but we have a vision of an aspirational education service for children with SEN which all of us must work to achieve.

The test for the Strategy will be where we find ourselves in ten years time. Will we be confident in recording that children with SEN and disabilities are learning and achieving more in all our schools? Will the pupils with the most complex needs be making progress, with parents and schools happy at the support they receive? I hope the answer will be affirmative. And I also know that we must all take responsibility in making it work. As the Audit Commission (2003) noted, when reviewing services for disabled children:

'We need strong leadership for change. It is no longer acceptable to perpetuate patterns of services that lead to social exclusion and inequality. But improving children's services does not only mean new structures and new approaches. There are examples of good services 'getting it right' and 'children's champions' in every locality. We need not only ongoing development but also mainstreaming of existing good practice.'

And finally, we should not forget the *Disability Discrimination Act 1995*, Part 4, disability duties in education. Pupils with PMLD have most to gain from this legislation and its related access planning duties. Progressive improvement in access to information, the curriculum and the physical environment will be essential to improved access to learning. The disability duties in education in effect provide an impetus to consider the needs of all pupils and to continuously review access as the school populations become increasingly complex.

Dr. Philippa Russell,
Disability Rights
Commissioner,
Special Adviser on
Disability Policy,
National Children's Bureau,
8 Wakley Street,
London ECI 7QE

Email: PRussell@ncb.org.uk

NEWS, PUBLICATIONS AND RESOURCES

New web site launched!

www.pscal.es.com



This new website has been created by the East Midlands SEN Regional Partnership 'P Scales Project' to support colleagues in the use and moderation of the P Scales.

What are the P Scales and what are they used for?



The P Scales are a set of criteria or performance descriptions developed by the DfES '...for measuring the progress of pupils for whom the early levels of the National Curriculum are not appropriate

(DfES, 2001), in both special and mainstream settings.

'The performance descriptions have been written for use with pupils of all ages and with a range of special educational needs. The descriptions are not a full description of all that pupils might achieve. They are intended to provide a framework on to which the progress of pupils, measured using the school's own assessment scheme, can be mapped. The descriptions do not replace the more finely tuned assessment schemes used for detailed individual assessments and curriculum planning by many schools. Rather, they complement those schemes by providing a common basis for comparing performance between pupils and schools'. (DfES, 2001)

The P Scales descriptions are designed to reflect early development of learning, leading into the National Curriculum descriptions of attainment for each subject. They are currently grouped into 8 levels (p1-8), with the 3 earliest levels (p1-3) each having 2 sections (eg p1i and p1ii, p2i and p2ii, p3i and p3ii). These 3 earliest levels reflect general development, rather than being subject specific. Later levels (currently levels 4-8) describe learning and development of a more subject specific nature.



Annie Fergusson (Project Co-ordinator, Liz Allison (Project Administrator), June Green & Sharon Leeson (Research Associates)

What's on the site?

What help will it give me?

The website provides a opportunity for sharing information about all aspects of using the P Scales for assessment, moderation and target setting. This site plans to combine work being developed by the research project together with information, materials and developments from schools and LEA's in the East Midlands region, and provide a national perspective. It will continue to expand as the project develops over the next 2 years.

The site has an interactive forum where we welcome your comments, ideas and queries. We would also appreciate examples of practice from you to include and share on the site. In addition, there are easy links to other useful sites, materials, publications and information.

For more information about the project contact us either via the website www.pscscales.com

or email:
Project Co-ordinator ann.fergusson@northampton.ac.uk

www.pscscales.com

or Project administrator liz.allison@northampton.ac.uk

Extracts in this information have been taken from DfES (2001) *Supporting the Target Setting Process* (revised Mar 2001) Publications Ref: DfEE 0065/2001

A **Health and Wellbeing “Toolkit”** developed by the Learning Disabilities Federation and North Tyne Side Primary Care Trust.

A communication resource to support people with learning difficulties in issues of health, healthcare and services.

It includes an introduction to health and wellbeing, a photograph storyboard booklet/CD ROM, a section for primary Care staff with information on learning difficulties.

For further information contact:
Alison Chalmers, Information and Communication Officer, Learning Disabilities Federation, 83 Howard Street, North Shields, Tyne & Wear, NE39 1AF. Tel: 0191 200 1013



‘Advocacy Strategy’

Mencap has launched a 3 year plan for supporting people with a learning difficulty to speak up for themselves.

To get a copy contact:

Kate Salter
Tel no. 0121 707 7877
E-mail:
kate.salter@mencap.org.uk



Living Your Life- the new edition

- *David Stewart, Headteacher of Shepherd School, Nottingham, provides information on this important sex education package.*

In 1988 Dr Ann Craft secured funding from the Joseph Rowntree Foundation to carry out the development of a training package for people with severe learning difficulties in the area of sex and relationship education. Working with colleagues from schools, colleges and day centres in Nottinghamshire, *Living Your Life* was produced and published by LDA in 1991. Ann followed up the publication of the pack with extensive national training. Sadly she died in 1997 whilst in the process of producing another package *Sex in Context* which was aimed at people with profound and multiple learning difficulties.

As with many successful products in the special education field, the original *Living Your Life* went out of print and as someone who had been involved in its original production and was keen to support a second edition, I was conscious that some of its terminology had become very dated and needed to be revisited. Undoubtedly had Ann lived, she would have wanted to undertake this task and we, the staff of a school for children with severe and profound and multiple learning difficulties, discussed possible approaches.

By 1999, it became clear that the thrust of the drive on sex education for the National Agenda was teenage pregnancy and that Nottingham LEA had the opportunity to bid for monies from the Standards Funds for this area of work. At the same time the National Agenda in relation to special education was, and still is, inclusion and with this in mind I submitted a bid to evaluate what was happening in terms of sex education in the City of Nottingham for teenagers with special educational needs in special and mainstream schools. Part of the project involved a review of *Living Your Life*.

The bid was successful. The research showed a dire picture in the Authority, which, sadly, was replicated in many other

authorities. Clearly very little was happening and staff felt unsupported, untrained and lacking in resources. In many mainstream schools, for example, no one appeared to be responsible for this area of work and little or no consideration had been given to who should be responsible. Should it be the SENCO? Should it be the Head of PHSE? Obviously the person ultimately responsible would have to face a steep learning curve.

Nevertheless, the re-editing of *Living Your Life* went well and involved working groups of staff and students. Consultants for the original work did not include 'service users' as it was then thought that the professionals 'knew best' and the views of people with learning disabilities were not sought. The involvement of students was therefore a major change, and a range of students from mainstream and special schools, day centres and colleges took part with some young people without learning difficulties providing another perspective. It was important that all those involved in the project should meet in pleasant surroundings and a good leisure centre was chosen which could provide enjoyable facilities. In addition tasty food was available and transport provided to and from the venue. An important element in the success of the project was the availability of a support worker or facilitator whose job it was to work directly with the students and who had a different role from the leader of the group. Her responsibility was primarily to ensure that students understood what was being said.

All the service users appeared to value being part of the group as they recognised that their views were important (and they had much to say!). One of the major changes that they advocated was that the aspect of living with a disability should be brought much more to the fore as those with disabilities felt that this aspect of their lives

was often ignored. During the discussions, the issue of fears for personal safety and bullying (in the community, at school or college) was clearly seen as real cause for concern.

The pack was revised and, with support from the Department of Health, is published by Brook Publications. It now consists of a main teaching pack, and a set of line drawings, which can be photocopied. This new version of *Living Your Life* was finally launched in November 2003 in the ballroom of the Council House in Nottingham. With a brass band playing, some one hundred and fifty people, many of them with special needs, watched whilst the young people spoke of their involvement in the project. How proud they were, and how proud we were!

The packaged is divided into modules which are subdivided into units. The modules cover the following areas. Group Building; The Physical Self; Emotions; Relationships; Sexual Expression; Choices and Consequences; and Personal Health and Safety. Each subdivided unit contains objectives, suggested teaching activities, resources and strategies for evaluation. There are also revision exercises for use at the end of each module. For example the Module on 'relationships' has 15 units:

1. self esteem;
2. presentation of self;
3. interpersonal social skills;
4. people close to me;
5. greeting behaviour – family members;
6. roles at home;
7. how roles change;
8. greeting behaviour – peers;
9. greeting behaviour – formal situations;
10. getting on with others;
11. forming relationships;
12. close friends;
13. girl/boyfriends;
14. sustaining relationships;
15. ending a relationship.

Notes available in the units highlight some of the difficulties that the students may face.

Those at the beginning of the unit on 'close friends', for example, state:

'It has been recognised that some students have very limited opportunities for friendships to develop... They may need particular help from teachers and carers with making arrangements to spend time outside school/college/centre with a friend. Teachers may need to work with parents and carers to provide opportunities for students to make and foster friendships.'

This unit considers: Why do we need friends? What makes a close friend?; How do we make close friends? Making and breaking friendships.

In addition to the suggested teaching activities, information on resources and strategies for evaluation, students are encouraged to say/sign/draw something good or new (that they have learned) at the end of the module.

In the production of the new edition we were also aware of the need to provide support and advice for those working with students with Autistic Spectrum Disorders and each unit makes reference to these students, and suggestions are made about strategies which might be particularly helpful for them. Information on their needs is also provided in a separate appendix. Other appendices contain planning and evaluation sheets; student record cards and sample letters to parents as well as a sample certificate for awarding achievement.

The challenge now is to ensure that staff know about the package and feel confident to use it. It is reasonably priced at £50 and is available from Brook Publications.

More information can be obtained from:
David Stewart, Headteacher,
The Shepherd School,
Harvey Road off Beechdale Road,
Nottingham NG8 3BB.

Email: shepherd_school@hotmail.com

or from:

Brook Publications
421, Highgate Studios,
Highgate Road,
London, NW5 1TL
Tel: 020 7284 6040

Body Works- Health and Sexuality Education

A scheme developed by Angela Mallet and Sarah Bustard to encourage self-awareness and the understanding of health and sexuality issues in pupils with profound and multiple learning difficulties.

Background

The Shepherd School is a school for approximately 110 pupils aged between 3 and nineteen years. Most have severe learning difficulties; about one third have profound and multiple learning difficulties. In the early 1990's the Shepherd School was providing 'Health and sexuality' sessions designed for pupils with PMLD, but the sessions tended to be disjointed and there was no overall cohesion. Consequently a scheme called *Bodyworks* was developed, and used to provide a structure and overall framework for self-awareness and well-being activities. The scheme was used consistently in the Shepherd School and other similar establishments, and staff felt that it was of great benefit to pupils, parents and carers, in addition to helping staff with planning and the recording of pupil responses.

In 2001 funding for the teenage 'Pregnancy Standard Fund' enabled the original *Bodyworks* scheme to be updated and revised.

Objectives and contents of the new Bodyworks Scheme

The revised scheme aims to develop self-awareness and understanding through a range of practical experiences that are intended to be enjoyable and fun. The resource is broken down into four sections encompassing the whole body:

- feet and legs;
- head and face;
- hands and arms;
- torso and neck.

Each of the above four sections is then subdivided into 6 themes:

- health and hygiene;
- appearance;
- independence
- protection;
- physical care;
- social and sexual awareness.

For each of the themes in each section, a range of activities is suggested, (together with ideas on the contributions that community visitors can make), are designed to provide awareness, understanding and involvement at early levels of health and sexuality education.

The use of Bodyworks

Bodyworks is flexible and it can be accessed and used in many ways; examples include:

1. Concentrating on one section of the scheme at a time (eg 'hands and face') and working through activities to improve awareness of the specific body parts.
2. Concentrating on one theme (eg 'appearance'), and working through all the body parts sections.
3. Using a *combination* of body-part sections and themes depending on the specific needs of individual pupils.

Whichever format is chosen, activities are seen as part of a total framework of body awareness and experience. Teachers are encouraged to include their own activities to further enhance the examples provided.

Recording and Dissemination

The revised *Bodyworks* also provides examples of how a pupil's individual involvement can be recorded (in magazine-style booklets). For example, in each of the four 'body parts' sections, three magazine covers are provided: one aimed for use with younger children; one for students; and one

for older people. Sample booklet pages include information on all the themes covered within the four 'body-parts' sections, and blank spaces are available on each page for information and comments that are specific to individual pupils, students or adults.

In addition to use in schools, the recording booklets can be sent home to provide parents and carers with basic information about the sessions and/or about the specific individual needs of pupils (eg: short skirts look nice on the beach but can be uncomfortable and cold!).

'Problem pages' and 'readers letters' are included in the magazine booklets in order to provide information and to generate awareness about a range of possible problems. These pages are especially useful in the sensitive areas such as 'torso and neck' and in the themes of 'social and sexual awareness'. The booklets can also be shared with siblings who may be interested in some of the comments. Space is available for additional information to be added on specific problems or issues for the pupils, staff and/or parents and carers.

Resources

Although sample lesson plans are included in the *Bodyworks* scheme. these can be easily added to; most of the suggested teaching activities are self-explanatory and give information on easily accessible resources. The majority of the materials described are everyday items that can easily be acquired, but where more unusual items are listed, names and addresses of suppliers are provided.

It is important to stress that the suggested

framework, but it is expected that teachers will use them in flexible ways to match financial resources, available curriculum time, the needs of students, and staff confidence.

Staffing levels will obviously vary from one organisation to another and, depending on ability levels, some students may need staffing levels of one to one, whilst others may be taught alongside their peers in groups of four. Staffing levels will also need to be adjusted to the level of complexity of the different teaching activities. The length of sessions, again will depend upon the individual needs of the students and may range, for example, from anywhere between five and 60 minutes. Some activities may benefit from specialist knowledge, and the use of visitors can be extremely helpful for both students and staff. Each section of the scheme includes ideas for visitors (for example, a hairdresser or a nurse).

Members of staff who now use the new revised *Bodywork* scheme feel that they have gained in confidence in providing education for pupils and students with profound and multiple learning difficulties. They are also of the opinion that the framework has given more structure and ongoing cohesion to a very complex curriculum area.

More information can be obtained from:
Angela Mallett and Sarah Bustard
The Shepherd School,
Harvey Road off Beechdale Road,
Nottingham NG8 3BB.
Email: shepherd_school@hotmail.com

Quality Communication:

Maximising Opportunities for people with Multi-Sensory Impairment

University College Northampton

24th & 25th September 2004



East Midlands Special
Educational Needs
Regional Partnership

Keynote Speakers

Eileen Boothroyd –Sense
Paul Hart - Sense Scotland



Barbara Miles - Communication specialist Consultant USA

For further information please contact: 01604 892695

A Task for Life

- a film about the lives of parents with children who have disabilities and special educational needs made by Danish psychologist Barbara Cros.

A Task for Life looks at the life situation facing parents of children with disabilities and special needs. It was made in Denmark and devised by the psychologist Barbara Cros, who explains that when studying psychology, and after working with children and adults with disabilities for some years, she realised there was a need for an educational film focussing on the situation of parents.

The birth of such a child radically changes the lives of many parents and the film examines the thoughts and feelings of five parents of four children and young people aged two to 19. At first it was difficult to find parents to take part in the research, but through the help of a large organisation for those with disabilities, she found 20 parents who were willing to become involved in the study. She was surprised at what she was told about the life-long emotional relations and practical problems that the parents faced and decided to tell their stories to help other parents.

Barbara Cros explains that the video came about as the result of interviews with the parents, but essentially focusses on the practical problems facing five parents. At the time of its making the video the ages of their offspring ranged from one to 45 years and therefore some parents were able to talk about a lifetime of experiences with their children, whereas others had only just discovered their child's disability.

Besides their individual experiences their stories also revealed a number of common factors and a clear shared chronology, covering:

- their reaction to having a child with a disability;
- the shock, grief and guilt experienced (some parents recovered with ease, whilst others had such feelings for the rest of their lives);

- the important period after the discovery and the practical, social and psychological consequences;
- living with a child with a disability who does not break away from his parents like other children;
- the effects on the parents' lives, on their marriages (and, in some cases, chances of finding new partners) and effects on other siblings and friends. In addition, their lack of spare time, the effects on work, their approaches to life and their ability to make plans for the future;
- contacts with, and dependence on, authorities, including social services staff, special needs institutions, day care centres, sheltered communities and respite care;
- the establishment of new values and realistic hopes for their child's future.

The parents (four mothers and one father) tell their stories from the moment they became aware of their child's disability, revealing their shock, grief, guilt and concern on the one hand and their worries about what would become of their child in the years that followed, on the other. They describe: their feelings for the child; their views on respite care and any training they received; their working day and the effect on their families; the way they see their own lives, their acceptance of new values, and the hopes they have for their children.

Since the 1970s in Denmark, children with disabilities and special educational needs live at home with their parents until they are at least 18 years old and are transported to school or day-care centres every day. The Danish ideology concerning women in the labour market has meant that mothers with children with disabilities are not encouraged to work and often stay at home and receive financial compensation. Consequently they become the chief 'coordinators' for their child.

Unfortunately, very few men were available to be interviewed, but the study features one divorced father, who had good communication with his ex-wife.

The parents who appear in the video are:

- Egil and Sonja, parents to 19-year-old Naja who has profound and multiple learning difficulties (including physical and visual problems);
- Inge, mother of Alberte. Alberte contracted meningitis when she was 13 months old and consequently her development is severely delayed;
- Helle, whose three year old daughter, Josefine, has Cri du Chat, a congenital condition caused by a chromosome defect;
- Heidi, whose two year old daughter, Alexander, also has Cri du Chat syndrome.

Although the video was originally meant for people working in the field of disabilities and special needs and has been used for the training of education personal, it has proved to be of use to other parents. It has been shown at conferences and courses and discussed in study circles, as well as providing vital information and encouragement for family, relatives and friends in similar situations.

Its importance is such that it was shown at the opening conference of the European Year for People with Disabilities in Aachen and is now widely available through all libraries in Norway and Denmark

A Task for Life is now available with English subtitles at £18 (plus postage and packing) and can be obtained from:

Barbara Cros,
Ved Bellahøj 13, A, 8,
2700 Brønshøj,
Denmark.

Tel: 0045 3860 2709

Email: barbaracros@hotmail.com

Major New Partnership between Contact a Family and the Royal College of Paediatrics and Child Health

Contact a Family and the Royal College of Paediatrics and Child Health (RCPCH) are working together in an exciting new partnership from 2004 to 2007, which has been made possible through a substantial Lottery grant from the Community Fund.

The partnership's essential concept is to create effective two-way communication between the parents of children with disabilities across the UK and the paediatricians who work with them. The project, ***Parents and Paediatricians Together*** has two main aims:

1. To ensure that every parent across the UK whose child is born or diagnosed with a disability or rare disorder is automatically put in touch, through their paediatrician, with Contact a Family.

We plan that, at this critical and very difficult point in their lives, this will give every parent and family access to the advice, support and information they need to meet the challenges of looking after their child with a disability, which will set them on a positive course for the future. We hope it will also mean that more families have a positive experience of dealing with paediatric services.

2. To open up new opportunities for parents of children with disabilities to influence paediatric and child health services across the UK, by creating new frameworks for co-operation between parents and paediatricians.

We hope this will mean a lot more families of children with disabilities will become directly involved in planning local child health services, to make sure that they best meet families' needs.

Contact a Family is leading the project and is appointing dedicated project officers in

England, Scotland, Wales and Northern Ireland. They will act as first points of contact for both parents and paediatricians, and will work closely with the local officers of the RCPCH to make sure paediatricians are able to refer families to Contact a Family. They will also develop the structures that will enable parent groups to become increasingly involved in planning child health services.

Contact details are as follows:

Contact a Family Scotland: 0131 475 2608 or at
<http://www.cafamily.org.uk/Scotland>

Contact a Family Wales: 029 2049 8001 or at
<http://www.cafamily.org.uk/wales>

Contact a Family Northern Ireland 028 9262 7552 or at
<http://www.cafamily.org.uk/nireland>

Contact a Family England 020 7608 8700 or at <http://cafamily.org.uk>

A Good Idea (From a patient)

This idea came about by accident. One of our very active little boys with autism, liked to push and spin the swing really fast, which was getting a bit dangerous. We thought we would divert this into something safer, so we attached some soft toys (some are noisy) to the washing line that the little boy could fling, without hurting himself or anyone else. He enjoyed this for a while, but like many children, he went off the idea eventually. However, Jesyca who was nearby really seemed to enjoy watching these toys, so we sat her wheelchair near enough that she could reach. Jesyca now really enjoys this activity while she is outdoors and will concentrate on the activity for ages. I suppose it's like a baby gym, but on a larger scale for outdoor use.



The Rough Guide to Accessing London

Contains 50 of the most assessable venues in London – theatres, cafes, parks and zoos. These venues were identified as part of 2003 European Year of Disabled People.

For a free copy telephone:

Reviews

The Use of Performance Criteria in the Assessment of Speaking & Listening: Supporting the Target Setting Process. Derby City Council

CD Rom and Booklet £9.00

This CD Rom is a resource designed to support schools in setting measurable targets within Speaking and Listening, using the P Scales and/or other performance criteria. It provides 30 video clip samples of pupils '...speaking and listening in a range of contexts and settings that show elements of the P Scale and National Curriculum indicators'. The pupil evidence is from special and mainstream school settings.

The video clips portray youngsters from the very earliest stages of learning (those with profound and multiple learning difficulties) through to those who have developed more sophisticated skills of communication and demonstrate attainment within the National Curriculum levels (examples up to Level 2). There are video examples to demonstrate the sort of evidence that might indicate attainment at each level of the P Scales (P 1i – P8) and through to Level 2 of the National Curriculum.

This valuable resource is the result of a group of practitioners from Derby City LEA, working through the target setting process. It very usefully provides a neutral source of materials, for use as a focus of discussion for school staff who are attempting to moderate evidence from their own pupils. The short booklet (2 pages) provides a valuable context for each video clip, highlighting the aspects of assessment that were agreed through this moderation. This in itself raises the important issues and discussion needed when making judgements through agreement trialling – for example, what aspects of this video evidence demonstrate one level and not

another? or, what else do I need to go back and check before I can say whether attainment of this evidence is at a particular level?

The CD ROM is designed for use in schools, but may also be a valuable training resource in other settings – for example, it offers valuable observations of individuals across the continuum of Communication. At only £9.00 – a bargain!

Annie Fergusson
Reviews Editor

In the Morning - The Dark Opens. A study of the experience of children with Down Syndrome and other learning disabilities in mainstream schools.

Research report compiled by Mairin Kenny., Eileen McNeela., Patrician Noonan Walsh and Michael Shevlin. National Institute for the Study of Learning Disabilities, Trinity College Dublin.

This report examines the experiences of a group of parents of children with Down syndrome in relation to the education, which their children received in mainstream settings in the Republic of Ireland. In particular the report focuses upon those stresses, which were seen to impact upon the families of the study students and the young people themselves, in both social and academic situations. It considers various stages in the lives of young people from early diagnosis, through assessment, making choices about educational placement and the ways in which access has been provided to the school curriculum.

As we have come to expect from this particular team of researchers, they have been careful to ensure that the voices of the research respondents are heard throughout the report. A series of interviews provided

an opportunity for parents to express their views and concerns in respect of all of the research issues. Reading these authentic views leaves us in no doubt that whilst there have been many successes in providing a more equitable education system for young people with Down Syndrome and other learning disabilities, there remains much that could be improved. Comments made by parents reveal difficulties with resourcing, professional insensitivity and a lack of flexibility in providing an adequate curriculum. However, the report is also keen to emphasise those positive aspects of inclusion, which have had a significant bearing upon the lives of the sample students. Parents speak enthusiastically about the positive relationships that have been fostered in mainstream schools. Equally important is the suggestion made by the researchers that school cultures are being positively influenced where teachers and managers are required to reconsider how schools are managed in order to provide for a more diverse range of learning needs.

This short (53 page) report is important in reminding readers of the critical interface between social and school experiences. The researchers have provided a balanced overview of the challenges, which remain en route to achieving a more inclusive society. It is to be hoped that the recommendations made at the end of this report will influence policy makers in the Republic of Ireland, but that they may also be noted by a much wider audience of school managers and teachers.

Richard Rose
Centre for Special Needs Education and Research
University College Northampton.

READ THIS >>>

**Do not forget about
the next issue of
PMLD  LINK**

Vol 16.2 Issue 48

‘Quality Services’

The editor of the next PMLD Link is Di Foxwell.

The copy date for all articles, information and news for the Summer/Autumn issue is the 1st July and the focus is on ‘Quality Services’.

Don't forget to send all contributions to Di Foxwell preferably in RTF (Rich Text Format or Microsoft Word (her contact details are on page 2). 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

Short Courses and Conferences

CONTACT DETAILS

BILD

Further details:

☎ 01562 723025

E-mail: learning@bild.org.uk

Catalyst Education Resources Ltd

1A Potters Cross

Wootton, Bedfordshire MK43 9JG, U.K.

Further details:

☎ and fax 0845 127 5281

E-mail: FloCatalyst@aol.com

Web: www.cerl.net

Costs:

£110 waged and professionals;

£80 learning support assistants;

£40 parents and unwaged persons

Sunfield PDC

Further details:

Sunfield PDC

☎ 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

Further details:

Alison Littlewood

☎ 01457 819790

E-mail: alison.littlewood@atandi.org

7 APRIL Making Advocacy Accessible

One day course to help people to understand communication and to use different methods of communication. It also looks at ways in which advocates can work with those who don't use words to communicate.

Organised by: BILD

Trainers: Lesley Johnson and Janet Badger

Venue: Kidderminster

21 APRIL Making Advocacy Accessible

One day course to help people to understand communication and to use different methods of communication. It also looks at ways in which advocates can work with those who don't use words to communicate.

Organised by: BILD

Trainers: Lesley Johnson and Janet Badger

Venue: Halifax

30 APRIL Sherborne Developmental Movement

Organised by: University College Northampton

Speaker: Steve Cullingford-Agnew

Venue: University College – Park Campus

5 MAY Advocacy Dilemmas

Day course to give participants some understanding of the current law around Consent and Capacity to make decisions. It also looks at parts of the Human Rights Act and how this information can help with some of the choices that advocates face.

Organised by: BILD

Trainers: Janet Badger and Ian Darch

Venue: Kidderminster

7 MAY Sherborne Developmental Movement Level II

Organised by: Sunfield PDC

12 MAY Master Classes on... *Emergent Literacy and Numeracy - Multisensory Approaches*

Organised by: Catalyst Education Resources Ltd

Speakers: Les Staves & Flo Longhorn

Venue: Luton

(Note: The same course is offered at – Oxford, 21 May and Central London, 9 June)

14 MAY 3rd Annual Catalyst Southern Conference
"The Cutting Edge - Best Practice in the Education of Children and Young Adults with Profound Disability"
 Organised by: Catalyst Education Resources Ltd
 Speakers: Barry Carpenter, Keith Park Robert Orr Richard Hirstwood Flo Longhorn
 Venue: Chancellors Hall Senate House Univ. of London (central London)

19 MAY Advocacy Dilemmas
 One day course to give participants some understanding of the current law around Consent and Capacity to make decisions. It also looks at parts of the Human Rights Act and how this information can help with some of the choices that advocates face.
 Organised by: BILD
 Trainers: Janet Badger and Ian Darch
 Venue: Halifax

20 MAY Intensive Interaction: Quality Communication
 Course designed for teachers and support staff and will include two workshops: Intensive Interaction and Multisensory Story Telling
 Organised by: University College Northampton
 Speakers: Melanie Nind & Kathryn Crosby
 Venue: University College – Park Campus

26 MAY Master Classes on...Educating with Multisensory Rooms
 Organised by: Catalyst Education Resources Ltd
 Speakers: Richard Hirstwood & Flo Longhorn
 Venue: Manchester
(Note this course is also offered at Leicester, 27 May)

28 MAY Dyslexia
 Organised by: University College Northampton
 Speakers: Liz Waine & Sue Kime
 Venue: University College – Park Campus

11 JUNE Seminar: Profound Autism - Hanging on to the End of the Autistic Spectrum
 Organised by: Catalyst Education Resources Ltd
 Speakers: Dr. Trevor Stevens, Diana Seach, Sally Slater, Flo Longhorn & Marlene Spencer
 Venue: Central London

23 JUNE Working Within and Around the Limitations of Vision
 Course for teachers, support staff, advisory staff and multi-agency professionals.
 Organised by: University College Northampton
 Speaker: Prof. Gordon Dutton
 Venue: University College – Park Campus

25 JUNE Inspiration Days Multisensory Approaches to Learning
 Organised by: Catalyst Education Resources Ltd
 Speaker: Flo Longhorn
 Venue: Salisbury
(Note this course is also offered at Hereford, 3 June)

7 – 10 JULY Transform 2004 – The New Assistive Technology Conference and Exhibition
 World Conference to explore the latest developments in assistive technology.
 Keynote speaker: Christopher Reeves
 Venue: University of Manchester Institute of Science and Technology

4-5 NOVEMBER 2-day Residential Workshop Working with teenagers and young adults with profound disability - learning for life
 Organised by: Catalyst Education Resources Ltd
 Speakers: Cathryn Crosby, Judy Denziloe, Flo Longhorn & Robert Orr
 Venue: Central London

AbilityNet Events
 Successful Computing on a Low Budget for Disabled People
 Successful Computing with Physical Disability
 Successful Computing with a Sensory Impairment
 IT Disability and Leisure Course
 For further information or to book a place contact AbilityNet on 0800 269545

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/pml/

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

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

Supporting Learners with SLD/PMLD*

***Subject to Validation**

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 pupil group. 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

Report Back

Understanding the Genetic Causes of Learning Disabilities: How knowledge can guide education and social practice

At this highly successful conference organised by the RSM Forum on Learning Disability and held in Dundee in October, three mothers, all members of PAMIS, courageously shared their experiences of caring for a son or daughter with a rare genetic disorder with an audience of around 150 people. They spoke alongside national experts who gave excellent presentations both on specific syndromes such as Fragile-X, Rett and Prader Willi, and on broader topics such as genetic counseling.

However it was Fiona Fisher from Fife, and Loraine MacKenzie and Cathy Heaney from Glasgow, who offered insight into the experiences of families with a child with a genetic syndrome and profound and multiple learning disabilities. As Fiona said, they did so because of a 'passion and desire to encourage everyone to help their son or daughter make their lives the best and most meaningful they can possibly be'. Their presentations, illustrated by family photos, introduced their children, Jonathan who has Lowe Syndrome, Catrina who has Aicardi syndrome and Edward who has Tuberous Sclerosis, each with very individual interests, relationships and needs – personalities who could have been hidden behind the technical language of modern medical science.

The parents described their feelings of shock and isolation after first being given the diagnosis of a rare syndrome for their child. However, they had soon become experts in their child's condition and could offer the medical profession and support workers valuable lessons. Dr. Jeremy Turk, President of the RSM Forum on Learning Disability and Professor Derrick Pounder, Regional Sub-Director of the RSM, congratulated them on their moving presentations and wished that all medical trainees could have heard their experiences.

The families' wish list for the future included:

- a key worker system to advocate for you when you needed support
- to be "taken as seriously as the professionals"
- good quality services from health, education, social work and housing
- continuity of services at transition
- up-to-date information and specialist support – especially at the time of diagnosis
- contact with other families – mutual support

A key message of the day was the value of genetic counseling. Obviously it is very important to families to know the implications of the diagnosis for the health of the person affected and whether or not a condition is likely to be hereditary. Some genetic conditions, known as *behavioural phenotypes*, result in the person exhibiting particular patterns of behaviour, information on which can be very helpful to families in making sense of what he or she does, and helps with early intervention programmes and learning and teaching.

The conference was a great example of sharing information and experience, and of partnership between medical professionals and families. This report appeared in *PAMIS Newsletter*, January 2004 and a fuller report can be found in the *RNIB Eye Contact* (Autumn 2003).