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PMLD LINK

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

CONTENTS

Involving People with Profound and Multiple Learning Disability – Representation and Consultation

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

VOL. 14 No. 3 Issue 43 WINTER 2002

EDITORIAL

I hope that readers will agree with me that this is a particularly informative issue on the topic of representation and consultation.

The scene is set by a parent describing her struggles to achieve an inclusive education for her daughter, Claire, and by Claire's personal assistants, describing how they see their roles as advocates for Claire. In the following articles the legal background is set out, examples of good practice given, information given about resources available to enhance participation of young people who do not use speech, and a directory of support services nominated as helpful by the users is described. A number of articles describe different approaches to giving people with communication difficulties a 'voice', and organisations which aim to support them in this. The theme even continues into the News section with a short description of the award winning 'Trans-active' project.

You will also see in the News section that PMLD-Link now has its own website, and we would welcome any comments, ideas for inclusion, and useful links to add to the list. Please send me your comments and ideas by e-mail, or any other means.

At the last Editorial Group meeting it was agreed to set up a 'Consultation Group' whose members would represent different disciplines and regions. Their brief will principally be to keep in touch with work in their area (or nationally) and commission articles reporting on innovations and interesting practice. They will be kept in touch with future topics and developments, and we hope that they will make useful comments and suggestions. Although they will not be members of the Editorial Group, they will be welcome to attend at any of the meetings.

We have only a small number of members on the Consultation Group at the moment, so if you are particularly interested in the field of PMLD and would like to support PMLD-Link in this way, or if you know of someone else in your area who might be interested in doing so, please let me know.

As you will see from Future Focus the next topic is on Leisure and Pleasure - I am sure that many of you have ideas and experiences that you would be willing to share on this theme. Do send them in – an article can be as short or (within reason) as long as needed to tell people about the interesting and enjoyable experiences that you have shared with people with PMLD.

Business Matters
Articles for inclusion in the next issue should reach me by 3rd March. Send by post or e-mail to the address below, and if you have any diagrams or pictures could you please send a hard copy.

This is the last issue of the current subscription year. A separate subscription form is enclosed for you to renew your subscription. For some recent subscribers this will seem very soon to resubscribe, but I hope you will feel that it is worth it.

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

FUTURE FOCUS - Leisure and Pleasure

As I am writing this future focus during the run-up to the winter holiday season "leisure and pleasure" seems a particularly timely subject for the next issue of PMLD-Link. I want to encourage you to share information with readers about the ways and means you have employed to enhance the leisure time of people with PMLD. In your experience what measures and ideas have been particularly helpful in promoting opportunities for the enjoyment and relaxation of your family member, pupils or clients with PMLD?

Looking back over the dozen or more years since I researched what leisure activities were available in Europe to people with PMLD, I am struck by the progress made in the UK in recent years towards the development of a society with a commitment to equal opportunities for the participation of all citizens. There is still some way to go to achieving this ideal, but advances are apparent. One positive influence has been the social model of disability with its focus on the environment as the key determinant of the opportunities available to people with impairments. The social model explicitly places our attention on ways and means of ensuring the environment offers access to stimulation, relaxation and a varied social life for all.

Another key advance in facilitating equal access to leisure opportunities has been the Disability Discrimination Act of 1995, the powers of which are gradually being extended and tightened. No longer can pubs, hotels and other leisure venues make people with PMLD unwelcome, as was still the case in 1990. Since 1996 it has been illegal for a business or organisation providing goods and services to treat disabled people less favourably than other people because of their disability. Since 1999 they have had to make reasonable adjustments for disabled people.

This gain in legal entitlements and the greater focus on the provision of an enabling environment for disabled people have produced a better climate for participation in leisure activities. However, leisure is a very individual matter, so that finding out what someone prefers is also paramount. It was interesting to me therefore to read this year about a consultation exercise concerned with leisure experiences, carried out with eleven pupils at Greenside School, an SLD school in Stevenage. An independent drama therapist was contracted to consult the children on a one-to-one basis, using drama, art and "fun activities" to encourage the children to communicate their views. The children's preferred leisure activities were very varied, and similar to those of non-disabled children (computing and shopping came out top). One development, emerging from the consultation was the setting up of two befriending schemes. Three of the children indicated they would like a befriender to take them to leisure events, and one child already had a buddy who supported them at a Saturday club. This type of initiative is, of course, one example of an environmental adjustment to promote participation in leisure.

What developments do you know of which have been successful in facilitating the leisure and pleasure of people with PMLD? Have you had positive experiences from which others can learn? Do write and share your ideas, experiences and views about how barriers can be overcome so leisure and pleasure is available to all.

Judith Cavet
PMLD-Link Editorial Group

Claire and her Education

At three, Claire went to a mainstream nursery for two years, where she played along side other children. Where she enjoyed listening to the chatter of other children and playing alongside them, but at the age of five that all changed, the other children were mostly going together to their new school but not for Claire, she had to tread a different path and on her own, so we polished up her wheelchair and went off in the school bus to a special school.

Claire was seven years old and had been in special school for two years before I realised that her disability was being used to define who she was. Professionals wanted to 'fix' her. I realised how damaging this was, because the professionals did not see her as normal. The special school was severely oppressing Claire and this was clouding her learning capacity. Claire's desire for companionship, achievement and a sense of belonging went unnoticed.

The need to change her environment was crucial, I was terrified to approach a mainstream school. But I was desperate to get her into mainstream school and was prepared to argue, cajole and plead for her to be accepted. We had already experienced the usual excuses that many parents of a child with disabilities hear, there is no disabled toilet, not accessible for a wheelchair, other children will suffer, the other parents will object. The professionals know what is in her best interest.

We were lucky to find a headmaster of a Primary school who believed that his school was a community school and everyone was welcome. Just recently Claire celebrated her 21st, and the headmaster of that school wrote saying:

> *"I have such happy memories of you at St. Simon's all those years ago, and of the very positive influence you had on our whole school. We were very privileged to have you as a pupil."*

Even though her experience at St. Simon's was a great success this did not mean Claire could automatically go to the Secondary school with her non-disabled friends. However, I knew this was where Claire wanted to be. The professionals were saying 'No' but her friends were saying 'Yes'. We had to endure many meetings with education officers, who were bullies and who intimidated me especially when I was on my own but after many anxious months and help from Claire's friends who wrote letters to the school and the authority, the school and the authority agreed to give it a try.

For some of the class teachers the notion of inclusive education with a curriculum shared by all are issues of high anxiety. Claire found this through all her mainstream attenadance. However, as teachers became more familiar with her, their anxiety dispelled. It is only through the actual process of inclusion that people stop seeing disabilities as a burden and drain on resources, but actually embrace the fact that it enables staff to develop new skills.

Although the school was inaccessible for Claire, a wheelchair user, and although Claire does not use speech to communicate, with the help of her friends the whole experience was a huge success even to those who initially had many objections. In the mainstream school the focus was on what she could do, whereas her experience in the special school was focused upon what she could not do.

After her secondary schooling Claire wanted to go on to the sixth form college and yet again I was expecting the same barriers. However, the vice principal was a person who looked for solutions and not problems. The solutions were not always what I wanted, but he clearly wanted Claire in the college and for me this was the most important issue.

Her three years there were an incredible success. She followed a varied curriculum embracing many aspects of college life. From the start it was termed 'Claire's Curriculum' and involved

Art, Aromatherapy, Chaplaincy, Drama, Ethics, Information Technology, Liturgy, Music, Psychology and Swimming. Whilst there Claire continued to promote inclusive education simply by placing the emphasis on 'being' rather than 'doing'. To quote the Vice Principal in his letter to her

> *"Almost always in life we do not realised how we touch people's lives. But believe me, you have had an incalculably positive effect on students and staff here."*

Although Claire has officially left the college she is still welcome to attend a couple of days a week to keep in contact with the many friends she has made there.

She now has Direct Payments where she can employ the assistance she wants, when she wants it and to do what she wants. During the last academic year she has attended modules at Bolton Institute of Higher Education where she has already 40 credit points towards her BA. I wonder what the professionals in 'Special School' would say now?

Pat Dolan

An Advocate for Claire

I'm Julian, I'm 18. I am one of Claire's personal assistants and her best friend.

I am also Claire's official advocate. As an advocate I facilitate friendships for her. When I take her to an ethics lesson, if they don't know Claire, I introduce her explaining about how she communicates.

I try to help her express her interests and views.

She enjoys when we are out together having a laugh because I am a bit of a comedian. I give her dignity, respect and choice.

I try not to impose my views on her and I am always encouraged by her parents to take on new tasks.

I love my time with Claire and I know she loves being with me.

Julian Singleton

Advocacy for Claire

I was surprised to be asked to write about advocacy. I have been a personal assistant for Claire for almost three months, and prior to this had very little experience of disability. Having grown up in the late 1960s and the 1970s, disability was an issue that was never mentioned, almost invisible, and so I started working alongside Claire with little to offer in the way of experience.

Having read a little about advocacy, I realise that I have been practicing it for thirteen years, as Dad to my three children. Being an advocate for Claire is not greatly removed from my experience at home, although I realise the decisions I have made for my children as they have grown older have sometimes not been appreciated, in fact, like all parents, perhaps my advocacy has sometimes been weighted towards helping mum and dad!

Each day with Claire is different, although some things such as medicine stay the same, and I approach each day with an open mind. As Claire has no power of speech I take care to make choices that I feel she would express given the opportunity, for example, with food. Claire has a varied diet, and usually a good appetite, but as I learn how she expresses herself to me, I am now able to decide what she may or may not want to eat.

Perhaps the best part of our short time together each day is when we go out for an afternoon walk. We tend to vary it on a day to day basis, after all, it would be boring for both of us if we went to the same place every day! At least twice a week we go down to the local park. Here, as I tell Claire, we can people watch. Along the way I will stop and chat with her, a small thing perhaps, but I feel it is important that Claire doesn't think that she is just being pushed around. Equally, when people talk to us when we are out, I make a point of crouching down at the front of Claire, that way no one can fail to notice there are more than two people in the conversation!

There is much more to our four hours together than this, bath in the morning, clothes, music, chatter, personal needs to name a few. My aim is to make each part as varied and as interesting as possible, bearing in mind what Claire wants. All Claire's personal assistants and her parents play a large part in her day, mine is just one small part of many. Each day is part of a learning process, for both Claire and myself, but I continue to learn more from Claire than she will learn from me.

As Claire can't speak and can't gesticulate, it is not possible for her to tell me what she wants, or indeed for her to put her head in her hands when I put the t-shirt on back to front yet again! However, I have learnt and continue to learn to understand when Claire is content, when she is happy, tired, uncomfortable or otherwise. What is important to note is that Claire has a fantastic amount of patience, a keen sense of humour and sometimes smiles seemingly endlessly.

I don't claim to know all Claire's needs, and obviously in time I will learn more about her interests, some may even say that I am only performing a minor role at the moment when it comes to advocacy. It is a fair comment, and perhaps in time I will learn enough to express on Claire's behalf on more complex issues, such as her role in the wider community and independent living. But it is equally fair to point out that the choices I make are informed and always driven, not by any personal desire or for my own self-esteem, but by a desire for Claire to continue to enjoy a rich and varied life.

John Humphreys

Advocacy for Claire

My relationship with Claire began 15 years ago. In all that time I have played many different roles e.g. personal assistant, educational assistant, facilitator and, most important, advocate.

Claire cannot express her needs verbally, so we have had to learn to communicate on a deeper level.

Through the years our journey has been very eventful. We have experienced many emotions that have brought us closer together.

Claire has a quirky sense of humour, she lets me know very clearly when she is not happy in a situation and I have to recognise when she is playing me up. I have always tried to represent Claire as a unique gifted person, her dignity, respect for privacy when she needs it are all high priority.

Advocacy is not always an easy role. There have been times when I have made decisions that have been more about what I wanted for Claire, not what she wanted. I hope I have learnt from these mistakes. The power in our relationship has to be equal. She has been a valuable friend to me and helped me through many difficult times in my life.

Today she is 21 years old and has many friends who are also advocates. We work together for a better future when Claire will be an independent woman in her own right.

Carole Sampson

Having a Voice: Participation in Decision-making by Children and Young People with PMLD

Introduction

Children's having a say in decisions which affect their welfare directly and indirectly is increasingly recognised as their right. Many reasons are put in favour of asking children about their views. It has been suggested that listening to children:-

- promotes more child-centred practice;
- promotes more effective services;
- helps to avoid abuse;
- encourages self-confidence and self-belief in children.

There have been a variety of initiatives aimed at seeking the views of children at school, children using the health service and children using social services. Children are no longer expected to be 'seen but not heard'. But how far has this shift in attitude extended to children and young people with PMLD?

The aim of this article is to explore the relevance of developments in consultation with children to young service users with PMLD. The article begins by setting out the legal background for the participation in decision-making for all children in England and Wales, and then identifies some models of good practice of relevance to children with PMLD. In conclusion, some issues are listed for the attention of practitioners involved in decision-making which affects children and young people with PMLD.

Rationale: Children's Rights

The Children Act, 1989, although principally focused on the welfare of the child (rather than the rights of the child) states in Section 22 (4) that whenever Local Authorities are about to make a decision concerning a child they look after, or propose to look after, they should "as far as is reasonably practicable ascertain the wishes and feelings of the child". Moreover, Section 22 (5) makes it clear that Local Authorities must give due consideration to the wishes and feelings of the child having regard to their age and understanding. These provisions of the Children Act apply to children and young people who receive respite care under arrangements made by the local authority, as well as to children in their care although this fact is often overlooked or ignored (Morris, 1998a). Guidance about the Children Act and its operation in relation to disabled children states:- "If the child has complex needs or communication difficulties, arrangements must be made to establish his views....Even children with severe learning disabilities or very limited expressive language can communicate preferences if they are asked in the right way by people who understand their needs and have the relevant skills to listen to them. No assumption should be made about 'categories' of children with disabilities who cannot share in decision-making or give consent to or refuse examination, assessment or treatment" (Department of Health, 1991).

Looking more broadly then the Children Act, the UK is a signatory of the UN Convention on the Rights of the Child. Article 12 of the Convention confers on the child "who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child". Article 13 states that: "The child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice".

The Human Rights Act 1998 (Article 10) requires that central and local government uphold a right to freedom of expression. Morris (2002) interprets this as meaning that people should not be blocked from holding or expressing their own views, or from receiving information. As will be apparent from some of the quotations above, many of these rights are hedged around by caveats and conditions, which recognise limitations in the capacities of children and young people on account of age, maturity and understanding. However, there is a growing body of opinion (see, for example, Alderson, 1993) that children are often more competent to make decisions than previously thought. In the case of children with communication and/or cognitive impairments, research studies and consultation exercises have been carried out which suggest that these children have views which can be elicited, given time, skill and sustained effort on the part of those seeking to consult them.

Models of Good Practice: Some Examples

Children's views can be sought about decisions affecting them as individuals (e.g. about their care and treatment) and about more public decisions (e.g. evaluations of current services and consultations about the shape of future services). Information exists which is relevant to both areas, and indeed the two are closely linked. Below four examples of positive practice are described:-

1 *Research with children with communication impairments*
Jenny Morris' report (1998b) describes the process by which she and co-researchers undertook a research study with thirty young disabled people, many of whom had communication and/or cognitive impairments, about the plans and provisions made for them by local authorities. The practical steps taken with regard to consent, planning visits, the use of facilitators, equipment and communication aids are set out.

2 *Consultation with service users about a residential respite service*
Marchant et. al. (1999) describe the process of consulting with 26 learning disabled young people. A wide variety of approaches to communication were used to elicit the young people's views including speech, signs, symbols, body language, facial expression, gesture, behaviour, art photographs, objects of reference, games, drawing and play. Each person received one or more individual visits, and a third of them participated in group sessions. The people who collected the data were independent of the service in question and usually were unknown to the young people consulted. One outcome of this consultation was that the unsatisfactory behaviour of two members of staff was addressed.

3 *Consultation at Greenside School*
Dunnington & Rosenbaum (2002) describe how eleven disabled children were consulted about their leisure experiences and preferences. The children's ways of communication varied from verbal expressions to the use of two switches indicating 'Yes' and 'No'. An independent drama therapist was contracted to consult the children on a one-to-one basis, using drama, art, play, music and picture cards. The authors note the need to respond to a range of non-verbal signs and cues which can easily be misinterpreted or missed altogether. The children took part in three individual and one group session. They received feedback on the issues they communicated and are to receive a pictorial report of the consultation which has helped to inform the planning of local leisure services.

4 *Consultation with disabled children in a new unitary authority*
Holme & Hanmore (2001) carried out a consultation with twenty three disabled children about the social care provision they used. Interviewers who were generally members of residential care staff were already familiar with the children from whom they collected information. However, they spent time collecting in-depth information about the children before consulting them. Support material (e.g. photographs, symbols, objects of reference) were employed to aid the consent process and data collection. The success of this consultation has led the social services department to adapt the approach to provide social workers with a means of ascertaining the wishes and feelings of disabled children.

Conclusion and the Way Forward

These studies and other similar examples indicate that all children can give information about decisions relevant to them if the following conditions are met:-

1 Adults are prepared to listen with respect.
2 A variety of means are utilised tailored to the needs of each individual child.
3 A qualitative approach is recognised as having value.
4 Adults have the right skills.
5 Adults are willing to expend the time and effort required.
6 The necessary communication aids and equipment are made available to children and young people requiring them.

There has been evidence of major deficits in this area in the past (see, for example, Morris, 1998c). However, there is now evidence of improving practice and the development of advice and guidance (e.g. Morris, 2002). Professionals in this field now have models to follow so they can hone their skills, and work to involve children and young people with PMLD in decisions affecting their lives.

Judith Cavet
PMLD-Link Editorial Group

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Please ......

write in with your experiences, comments, ideas about representing and consulting with people with PMLD.

Or..... send in an article about the next topic – leisure and fun and let us know about any equipment playthings, leisure resources etc. that you have found particularly useful. Tell us about any articles journals, books ,videos or courses which have changed your way of thinking or of doing things.

PARTICIPATION: What helps make this a reality for children and young people with Profound and Multiple Learning Disabilities?

Although the last 10 years has seen an explosion in the number of projects and initiatives that focus on the participation of disabled children and young people, for youngsters with profound and multiple learning disability this 'participation industry' has largely passed them by. If you are a teenager with a physical impairment you may well be experiencing 'consultitis' as researchers and agencies fall over themselves to seek your views. However, for younger children and young people with PMLD, the participation methodology is poorly developed and sufficient resources rarely made available to make full involvement in decision-making a reality. All of this means that the very young people who are major users of services (e.g. hospices, home care and other short breaks) are the least likely to have their views taken into account.

The National Service Framework has participation as one of its key messages. The Work in Progress draft of the External Working Group for Disabled Children states "Disabled children should be supported to participate in all mainstream and community services so that they have the same opportunities as their non-disabled peers". This covers the involvement of all children in their own assessments, plans, treatment and care and in service development. For the External Working Group "all children" means *all children* and includes children with PMLD. This draft document acknowledges that in order for this aspiration to become a reality there will need to be substantial investment in training, facilities and equipment across all the agencies that work with young people with PMLD. To view the full text of the Work in Progress go to: -www.doh.gov.uk/nsf/children/externalwgdisabled This website also carries a detailed paper on participation which is also available from: -
Natalie.Moorcock@mencap.org.uk Tel. 020 7696 6019

The issue that comes up most frequently from practitioners is the lack of tools to assist them in seeking the views of young people with PMLD. Although some very creative ways of making progress in this area have been developed by practitioners in education, health, social care and leisure, there is a dearth of published guides to methodology and the use of new approaches. The research evidence base is included in the article by Judith Cavet. The following listing of resources includes those that have been published that may be useful for staff and carers working with young people with PMLD. This is a mix of resource packs and publications that are explicit about the use of methods to enhance the participation of young people who do not use speech.

Ask Us is a CD-ROM resulting from a multi-media consultation that involved over 200 disabled children and young people across England, aged between 4 and 24 years old. The aim of the consultation was to influence the Quality Protects programme by gathering the wishes and feelings of disabled children and young people. Many of those who participated have labels of severe learning disabilities and challenging behaviour. Some do not use speech or sign language; they express their wishes and feelings in other ways. *Ask Us!* is available for £5.50 from the Children's Society, Publishing Department on 020 7841 4415. For more information, please contact www.thechildrenssociety.org.uk

Ask Us2! CD-ROM, looking at children's rights will be available in Spring 2003, when both CD-ROM's will be available as a video package.

I'll Go First This pack is designed to support the involvement of children in planning and reviews by the Children's Society. This is a set of 16 wipe-clean boards about situations relevant to disabled children and young people. Colour illustrations and simple sentences (with Rebus and Makaton translations) are printed on the boards, e.g. 'these are the important people in my life'. 150 re-usable stickers illustrate activities, objects, people and feelings. You can also write or draw on the boards and add the child's own photographs, and the boards can be photocopied for reviews etc. The toolkit is suitable for children who have good vision and can attribute meaning to the stickers. *"I'll Go First"* is available from the Children's Society on 020 7841 4415 at £60.00. For more information, go to www.thechildrenssociety.org.uk

Listening on all Channels - Consulting with Disabled Children by Ruth Marchant was produced 1999. This report describes the process and rationale of a consultation with learning disabled children and young people about their use of a residential respite care service. The consultation attempted to give control of the agenda and the process to the young people, and to listen 'on all channels' to their views, which were communicated through speech, sign, symbols, body language, facial expression, gesture, behaviour, art, photographs, objects of reference, games, drawing and playing. *Listening on all Channels* sets the work in context nationally; outlines the planning and preparation tasks; reflects on initial approach to families and young people, reflects in detail on individual visits, groupwork, struggles to communicate and how to write up information gained. *Listening on all Channels* is available from Triangle in Brighton on 01273 241015 and it costs £6.00. For more information, please contact www.triangle-services.co.uk

Two-Way Street is a training video and handbook by Ro Gordon and Ruth Marchant 2001 and is about communicating with disabled children and young people. This has been developed in consultation with disabled children and young people, and designed to improve professional practice in communicating and consulting. The video provides an accessible teaching resource, combining practical information with a clear value base of participation and empowerment. The accompanying handbook (also available separately) gives further information and details of the most commonly used augmentative and alternative communication systems. This pack costs £55.00, while the handbook only costs £9.50. These can be obtained from the NSPCC on 0116 234 7223. For more information please contact Triangle on 01273 241015, email:info@triangle-services.co.uk or sferrar@nspcc.org.uk

How it Is is an image vocabulary for children about feelings, rights and safety, personal care and sexuality. It has been jointly produced in 2002 by Triangle and NSPCC. It was developed to support children to communicate about a range of important issues. It is designed to be used as a flexible, child-centred resource. There are 380 images available for free download from www.howitis.org.uk or as a booklet with a CD-ROM. The images were put together with the involvement of more than 100 children, and are designed to fill the gaps in existing symbol vocabularies. Most relevant for children already using AAC (alternative and augmentative communication) but suitable also for children who have limited language or understanding but are not formal AAC users. For further information contact NSPCC on 020 7825 2500, www.nspcc.org.uk or www.triangle-services.co.uk

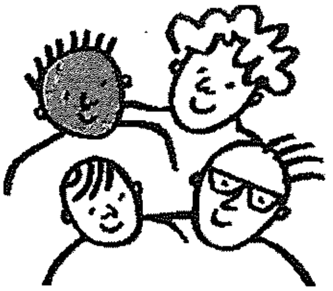
Listening to Young Children: The Mosaic Approach by A. Clark and P. Moss was produced in 2001. Although this methodology has been developed for pre-school children there are several elements that are useful across all age ranges. The *Mosaic Approach* is based on the premise that children are experts in their own lives and involved obtaining information on their expertise from detailed observation, the use of photos and video, mapping their use of the facility and seeking parents perspective. This is available from the National Children Bureau Books on 020 7843 6000. For further information, please contact www.ncb.org.uk

A Lot To Say by Jenny Morris was produced in 2002. It A guide which offers advice and information to social workers, Connexions personal advisors and others working with children and young people who have communication impairments. It will be of use in a number of settings - health, social services, education, and private and voluntary sector agencies. It is aimed at professionals who are not specialists in communication impairments, but who have responsibilities to assess the needs, and seek the views, of this important group of children and young people. It draws on the expertise of both those who work with young people with communication impairments and young people themselves. This is available free from Scope Library and Information Unit on 0207 619 7341 or email: information@scope.org.uk

Listen Up is a new Mencap project focusing on complaints and is developing a range of multi-media resources to enable all disabled children to make complaints about the services that they use. Amongst the range of products will be a staff training video and guide. The pack will be available in December 2003. For more details about this project please contact: - Ruth.Meaden@mencap.org.uk

Mencap has collated a listing of a wider range of resources. This is available from Natalie.Moorcock@mencap.org.uk

Lesley Campbell
Mencap



SHARING VALUE

Introduction

The Sharing Value Directory is a UK-wide, web-based directory of around 1300 support services for disabled or chronically ill children and their families which children and families themselves have nominated as 'really good and helpful'. Many of the services listed are relevant to children with profound and multiple learning difficulties.

The directory was produced from a two and a half year collaborative research project between the University of York, Barnardos and the Family Fund Trust, which was funded by the National Lotteries Charities Board. Sharing Value recognised that although there are many good services providing support for families with disabled or chronically ill children, families and practitioners are often unaware that these services exist or do not know how to contact them. The Sharing Value Directory aims to plug this information gap and help families and practitioners easily obtain and share information.

The Sharing Value directory provides an example of research working in partnership with service users and providers, as we worked with advisory groups of disabled young people, parents and multi-disciplinary practitioner groups at each stage of the research. Parents and practitioners conveyed their views through small and 'whole' group discussions and disabled young people were encouraged to express their ideas through a range of verbal and visual methods. For example, discussions, writing, drawing and, where appropriate, through the use of cards with rebus symbols and pictures of 'happy' and 'sad' faces, which the young people posted in good and bad boxes.

Methods

We collected 'valued' service nominations from a large survey of families with disabled or chronically ill children. A random UK wide sample of around 15,000 families with children from 0-18 was drawn from the Family Fund Trust (FFT) database[1]. However, the Trust has an income cut off for eligibility for grants, so in order to broaden the sample to include families from a higher income bracket, adverts were placed in a range of voluntary organisation's newsletters, magazines and national newspapers. This produced a small supplementary sample of 53 families.

Every family was sent three colour-coded questionnaires (one for parents/carers, disabled children and siblings) inviting them to nominate any really good support services that they use or have used in the recent past. Children were asked to nominate one service and parents up to two. Support services were loosely defined as 'any place you go to, any activity you do or people you see who help and support you' (children's questionnaire) and 'any place or person that has provided practical, financial, emotional or social support' (parents questionnaire). We did not include teaching or medical services. The content and design of the questionnaires was developed in collaboration with the project's consultation groups. Indeed, parents, children and practitioners helped us define 'quality' in support services.

Parents and children were asked to provide contact details of their valued service(s) and to indicate the type (or types) of support it provides and the reasons why it 'stands out as really good and helpful'. In order to make the children's questionnaire as accessible as possible, they could write down their ideas, tick boxes or draw a picture.

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[1] The FFT is a registered charity providing grants and information support to families with disabled and seriously ill children.

The response rate from families was 43 per cent[2] Overall 4336 respondents recommended a service: 2919 parents; 760 disabled children/young people; and 657 siblings. In total 5635 service nominations were received. This amounted to 2753 different services nominated as many were nominated by more than one family. Each nominated service was subsequently contacted and invited to participate in the Sharing Value directory. Just under half (1,293 services) agreed to be included in the directory. In addition, around 200 are described in greater depth. These 200 services were visited by FFT Visitors[3] from a shortlist drawn up with the help of parents' and young people's consultation groups. Drawing on the Sharing Value questionnaire's quality indicators that had been decided earlier with the consultation groups, parents' and young people's consultation groups were asked to highlight the indicators that they felt different types of services should ideally have. The services which met all the key criteria highlighted by the consultation groups were then visited.

Quality in Services

The children's and parent's groups identified some criteria as important for any type of service (Mitchell & Sloper, 2002).

For children these were:
Staff understand about my illness or disability
Staff know how to help and look after me
Staff listen to me
Staff ask me for my ideas and take notice of what I say
I can ask staff questions and they explain things to me
Staff allow me to make choices.

Parents' important criteria for any service were:
Meeting the child and whole family's needs
Listening to the child and family members
Treating the child and all family members with respect
Staff knowledge and training
Welcoming and helpful staff
Service respects family's culture.

The Website

The web based directory draws together service nominations and information into an easily accessible and up-to-date tool for both families and service providers. The directory lists the contact details of all the services that agreed to take part, as well as service 'summaries' of the visited services. These summaries contain more detailed information such as the aims or philosophy of the service, its organisation, funding and staffing, and the key to its success.

Parents guided and advised the researchers on the website's accessibility. A welcome page introduces the directory and guides visitors to the search section or to sections providing further information such as how to use the site, background information on the project and how to nominate services not already listed in the directory. The website can be easily and quickly searched by service type or by geographical region or country or a combination of both. There is also the facility to search by UK-wide services since some services, such as the Family Fund Trust, support families throughout the UK. In addition, some services, such as Crossroads, belong to a network of branches or offices, either on a UK-wide, national or regional level: contact details for these localised services are linked to contact details of their service's head office.

The Future

The research project has now finished and the Family Fund Trust has taken over responsibility for the web-based directory. With the help of Barnardo's Research and Development Team, the FFT are seeking funding to update and further develop the website. An on-going steering group has been formed to guide this process, with representatives from the Social Policy Research Unit, Barnardos and the FFT. However it is agreed that whatever future direction the Sharing Value Directory takes, the focus will always remain on services that are commended by the families that use them.

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[2] This figure includes families who did not have a service to nominate.

[3] FFT Visitors are health, social care and educational professionals employed by the Trust to visit families initially applying to them.

The Sharing Value Directory is available at www.sharingvalue.co.uk.

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References

Mitchell, W. and Sloper, P. (2002) Quality services for disabled children. Research Works, Social Policy Research Unit, University of York. Available free from Social Policy Research Unit at the address above or on www.york.ac.uk/inst/spru

The Advocacy Consortium

Scope, in conjunction with other national disability service provider organisations and umbrella advocacy organisations, have recently set up a consortium to look at the issue of independent advocacy provision for people with sensory, physical and communication impairments, and people with profound and multiple impairments.

Advocacy is 'taking action to help people say what they want, secure their rights, represent their interests and obtain the services they need.'

The Advocacy Consortium (Independent Advocacy Campaign) was developed out of a concern for the lack of independent advocacy provision for people with sensory, physical, communication impairments and profound and multiple impairments. The provision of advocacy for this client group is very limited and they are often excluded from taking an active role in society.

The members of the consortium believe the lack of advocacy provision is a result of two factors:

- Lack of funding to provide independent advocacy for this client group.
- Lack of knowledge or developmental initiative to provide appropriate advocacy provision for this client group.

The government's White Paper *Valuing People* has identified money available for the development of independent advocacy provision for adults with learning disabilities. Whilst we welcome this move, we are concerned that no plans have been made to meet the advocacy needs of people with physical, sensory and communication impairments.

The Consortium aims to develop a campaign that will inform policy makers and government for the need of greater long-term funding for the development of a range of advocacy needs of people with physical, sensory and communication impairments. The Consortium has sent a letter to all advocacy organisations it is aware of in England, to ask them to 'sign up' to the campaign. As a signed up member, organisations will be kept informed of the progress of the campaign and may be asked to participate in local lobbying.

If you would like further information about the work of the Consortium, please contact either:

Wendy Lewington, Scope Advocacy Co-ordinator
tel: 0207 619 7378 e-mail: wendy.lewington@scope.org.uk

Howard Lewis, Co-ordinator Advocacy Development RNIB
tel: 0207 391 2015 e-mail: Howard.Lewis@rnib.org.uk

Rick Henderson, Directory Advocacy Across London
tel: 0207 820 7867 e-mail: rickhenderson@btopenworld.com

Representation, Quality and 'Small Things'

Quality Assurance and the service user

'Quality' is a widely used word. It is defined in various ways and there are many different management approaches to quality assurance. In the residential sector, providers, commissioners and regulatory bodies all play a part in defining, setting and measuring quality - but what place does the user have in all this?

In Hackney, the local community health trust and Acting Up have worked together to develop an approach to quality assurance in a residential home for people with profound and multiple learning disabilities.

Acting Up's Multimedia Profiling

Acting Up, part of Matchbox Theatre Trust, has been working with people with communication difficulties since 1987, and has pioneered multi-media communications' training with services in the voluntary and statutory sectors.

With the advances and availability of digital technology, Acting Up has developed an innovative communications' tool, Multimedia Profiling. Acting Up's Multimedia Profiling (MMP) supports people to represent themselves and exercise greater control over the planning of their lives and the support they need. The techniques and process of MMP foster user-involvement through a live, hands-on working partnership between service users, carers and practitioners.

A Multimedia Profile is a computer-based catalogue of an individual's activities and personal history. It uses a range of media – stills, sound, video clips, graphics and text – to ensure the information is fully accessible. The service user is then able to share their day-to-day and long-term needs and aspirations with family, care workers, advocates and others.

For people with severe communication difficulties, Acting Up aims to turn the idea of user-involvement in care planning and care management into a reality.

MMP, Quality and User-Involvement

In the residential home in Hackney, MMP has focused particularly on the small things of day to day lives of the residents. It has been increasingly effective as a tool to enable service users, previously marginalized by severe communication difficulties, to be at the centre of defining and measuring quality in their own services

Small things can be difficult for an organisation to get right. Bureaucracy, attitudes, time, systems and structures can all get in the way of the provision of flexible and individually responsive services. Such small things include: providing on a regular basis food which a user enjoys, having a comfortable seat that is placed where a user wishes to sit on that particular day, being supported in personal care task in ways which take into account individual wishes. In the context of legislative, contractual and other requirements, these things can appear minor. Put in the context of a user's life, they are not! They make up a large part of every day and may happen every day over many, many years. They are also fundamental to the respect and dignity afforded to users.

Capturing the 'Small Things'

Its is often possible in an ad hoc way 'to get a feel' for how a residential home is being run and to pick up indicators of the extent to which the individual user's needs and wishes are being met. However, if the small things are put at the centre of the quality agenda then they have to be captured, recorded and assessed in some systematic and accessible way.

In 1996, The City and Hackney NHS Trust commissioned Acting Up to set up a computer-based resource in a residential home in Hackney, and to begin the production of multimedia profiles and staff training. The home in question supports 14 people and there had been a history of institutional practice. The objectives of the Trust were to bring about positive changes in practice and inform ongoing planning for re-provision of residents to more appropriate community-based housing.

The introduction of multimedia techniques and the new approach to quality has impacted on many aspects of the service. The use of individual profiles which pay attention to small things has moved the culture of the home away from an institutional one, much more towards putting users' needs and wishes at the centre of organisational arrangement. If the drivers within the management of the home are the users who live there, then work practices are developed from their point of view rather than from organisational or even staff perspectives.

Multimedia Profiling in care management.

Individual care reviews have been re-launched with the home, using profiling techniques to involve users in their own reviews. Reviews have taken place often over a whole day. Playing back personalised sounds, still and moving images, especially when prepared in advance with individual residents, has provided for the first time a way for users to be comfortably and meaningfully involved in their own care reviews.

There has also been a significant impact on staff performance. The profiles have been used as part of staff supervision and training sessions to encourage a reflective approach to practice. Staff are able to use individual profiles to examine aspects of their support, enabling them to understand in more detail and depth individual need and preference.

Profiles are also useful in passing on information in a form that is both precise and easily accessible. This method can be used to induct new staff and will be very important after the re-provision process when users will be receiving services from new providers.

User-involvement is central to the whole approach. This offers a particular challenge to services which are supporting people who do not use verbal communication. This is where MMP, sometimes facilitated by the use of customised assistive technology, is important.

It is evident within the home that this approach to quality assurance has made a real difference to services provided from the users' perspective. If this focus on the small things is to have such an effect on services then there needs to be a shift of emphasis. For staff, the work focus and indicators of good practice need to encompass the small things. Contracting and monitoring processes implemented by senior managers, commissioners and inspectors need to build in incentives to get the small things right.

Although this approach is being developed in a residential setting, issues are transferable to other care and support settings. By using new multimedia techniques, users can drive the process themselves and everyone can enjoy it! Care planning decisions are taken that are meaningful for users themselves – users without speech can make choices, have a say in their future, can look and listen to video, pictures and sounds about themselves and those close to them – on a regular basis, updated whenever circumstances change. The process can be empowering for a wide range of service-users disadvantaged by communication difficulties. By capturing and presenting the significance of the small things in day to day living, they are measuring, defining and assuring for themselves and in their own terms, the quality issues.

MMP in action

Len's multimedia profile was one of the first to be developed. His reputation was of a grumpy, self-isolating person who always sat pointlessly by the window, messing the window-pane and twisting up the net curtains. It emerged that at the window he had a vital engagement with a much wider world outside – a rich source of stimulation of his own making and choosing. The profile started to suggest an alternative story of Len's interior life. It showed Len's awareness and attempts to communicate. This new way of looking at Len and his world changed attitudes and approaches to his care. Frustrating barriers to independence were removed and Len found it safe to be more sociable.

The extracts below from notes of recent pre-review and review meetings show how the use of MMP has enabled meaningful representation and involvement for Len in the review process.

Len's Pre-Review Meeting
Irma opened the computer room, Len saw her do this and immediately wheeled himself in. He positioned himself in front of the computer and took Irma's hand to bang the computer. Irma started it for him and he continued to use her hand to bang part of the computer to get it going.

To start with we played the video of the helicopter.

(The previous month, 'out of the blue', a helicopter had made an emergency landing on the back lawn of the home. Len had been at his window to witness it, and staff had grabbed the camcorder to record the event).

We are agreed that the helicopter experience had been an important event for Len and that we would play the video to start the review.

Len now turned his attention back to the computer clearly wanting to see more. His 'Active Involvement' multimedia report was played. (Len now sometimes helps sorting his laundry and hoovering).

We all watched and talked through the main agenda items for the review.

Len's Review
Len took himself towards the monitor and positioned his chair besides the monitor and in front of the window. The review started by playing the helicopter video. Lionel listened and turned to look at the screen alternately with looking out the window.

The 'Active Involvement' multi-media report was played. In the report, there are three sequences where Len is being supported to hoover his room. Len smiled each time he heard the hoover noise, holding his head in a listening way on the third sequence, despite wanting to eat his cake at the same time.

He spent most of the remainder of the meeting alternating between times when he was still and silent and apparently listening, and playing with the curtains.

During discussion about his leg exercises, he seemed to listen, especially when a demo of them was shown on the multimedia. He also watched the demo of him being supported to eat, and he smiled at this.

Near the end of the meeting, Len wheeled himself across the room towards the door. Kath asked if he would like to watch the helicopter video again. It was started and Len got very close to the monitor. This time he watched it with his arm over the top of the set.

This marked the end of the review and Len left the room.

Kathryn Downton, *formerly General Manager, the City and Hackney NHS Trust*
John Ladle, *Director, Acting Up.*

For more information about Acting Up and Multimedia Profiling, please contact John Ladle on 020 8533 3344. Visit Acting Up's website at www.acting-up.org.uk

Supporting People to have a better Range of LIFE OPTIONS

SCOVO (the Standing Conference of Voluntary Organisations) is the collective voice of the voluntary sector in Wales, promoting the right of people with a learning disability to lead valued lives.

We:
- Work in partnership with other organisations, service users and their parents/carers;
- Campaign to help people achieve valued lives;
- Support the voluntary sector and its interests;
- Provide and promote good practice.

Following major concern from our membership, which was also backed up by recent research, we launched the 'Life Options' project in March 2001. The project is supported by the Diana Memorial Fund.

Over the 3 years of the project we aim to:
- Demonstrate how young people with profound and complex disabilities can be assisted and encouraged in their transition to adulthood;
- Influence the planning processes available to young people, promoting the importance of person centred planning;
- Disseminate practical information about this work, allowing many more people to benefit from our experiences.

The areas of life that individuals need support with include:
- Accessing good quality information;
- Having a 'voice';
- Control of money and resources;
- Having good health support;
- Getting around;
- Friends and support;
- Learning opportunities;
- Having fun;
- Daytime opportunities and work;
- Having a break;
- Housing choices.

As a demonstration project, great efforts will be made to share information about our activities through our information service, SCOVO's magazine, participating in conferences, and by producing a practical case study pack.

If you are a disabled young person, parent or carer, teacher, provider of services or an individual who is interested in the progress of the project, we urge you to contact us. We hope that the project can inspire you to make changes which offer people a better range and quality of life options, because we believe that...

With the right support, anything is possible!

For further details, please contact:
Mark Williams or Kelly Gammon
SCOVO Life Options Project, Stebonheath Centre for Enterprise, Stebonheath Terrace, Llanelli, South Wales, SA15 1NE
Tel: 01554 746782 or 01554 746806
Email: lifeoptions@scovo.org.uk

Advocacy and Circles of Support

"Effective advocacy can transform the lives of people with learning disabilities by enabling them to express their wishes and aspirations and make real choices. Advocacy helps people put forward their views and play an active part in planning and designing services which are responsive to their needs. This applies to people with severe and profound disabilities and to the less severely disabled" (Valuing People 4.5).

This is a direct quote from Valuing People (DoH, 2001) that goes on to acknowledge that the development of advocacy services across the country is 'patchy' and that there are many potential barriers to new initiatives such as conflict with statutory organisations who provide funding. The section goes on to point out that "this must change" and yes, it must.

There are, as we all know, too few projects, schemes and agencies who are there to assist people who have a learning difficulty to advocate for their wishes and wants. There are even fewer that have a focus on supporting individuals who require high levels of support. Those projects that do exist, often do not have the capacity in time, staffing or other resources to spend with a person who is perceived as having a 'profound learning disability'.

One way of addressing this shortfall and in changing the current situation is to enable a person with a high level of support need to build a Circle of Support around themselves.

Circles of Support are one way of ensuring that any person who is experiencing social exclusion (e.g. a disabled person) has their own 'voice' and is rightfully heard and responded to by others - particularly those who commission and provide services.

Circles of Support work by gathering up a group of people who agree to commit to the 'focus person' in assisting them to plan for a more meaningful and desirable life. This group of people is made up from family, friends, neighbours, community members and, at times, committed support workers who meet at regular intervals with the focus person to truly listen to what that person is saying. Circles of Support include people who are in there 'for the long run' as opposed to a number of interested professionals who often merely see a 'snapshot' of a person's life. The values behind having a Circle of Support are those of friendship, long term commitment and inclusion. This is not to say that committed professionals cannot offer invaluable support, but rather that there is a distinction of roles and an understanding made between a supporter or professional who spends time with someone because they are paid to do so, and a friend who wants to spend their time freely with that person. (In some situations there are paid workers who volunteer their time to get to know somebody much better and either request to be in somebody's Circle or preferably are invited in).

CREDO East (and previously the CREDO project) is a project managed through Circles Network and funded by the Community Fund. Its aim is to develop Circles of Support around teenagers who have a high level of support need and then assist in developing a person centred plan for the young person.

As Circles are made up of people who know the young person better than anybody else and who care more than anybody else, the chances of representing that young person's 'voice' are at a premium. This way of advocating for somebody is more efficient and potentially much 'safer' than citizen advocacy where a one-to-one relationship can breakdown due to pressure or a clash of personalities. Circles involve a number of people who share out the responsibility of assisting an individual who has usually lived a lifetime of being oppressed and who brings with them difficult situations and feelings for others to face up to and challenge.

A Circle is able to listen truly to a person who often communicates in a unique way. People involved have a lifetime of knowledge of that person and are therefore the ultimate experts in who the focus person is, what 'makes them tick', what are their favourite and least favourite things and what are their dreams and ambitions, to name but a few. Listening is not just about encouraging somebody to use pictures or symbols, it is about valuing every way in which a person communicates - through eye contact, movement, touch, breathing and silence.

"When it is genuine, when it is born of the need to speak, no one can stop the human voice, it speaks with hands, the eyes or pores or anything at all." Eduardo Galeano

Circles of Support are an excellent way of enabling a young person with high levels of support need to consult on what they think about their current support package and what would best suit their highly individualised needs. A Circle, in addition to supporting the focus person to feed this information to those who need to know e.g. service providers, also provide opportunities to empower them to ensure that change actually happens and that people are heard and not just listened to.

Circles Network has an educational objective to teach others how to build Circles of Support and to facilitate the process of Person Centred Planning both of which grew from the inclusion movement.

A Circle of Support, guided by a facilitator is indeed the best tool in which to develop a person centred plan around an individual. It means that the completed plan and the knowledge that the Circle holds of the person is the most accurate way of representing who the person is and what they want from their life. This then gives a young disabled person the best chance of being represented accurately and of having their ambitions met, bringing their dreams closer to reality.

If you would like to find out more information about CREDO east or Circles Network as an organisation then please:

visit our website: www.circlesnetwork.org.uk
or email: Nadine@circles.free-online.co.uk
alternatively you could contact by telephone on 01733 551253.

Nadine Jay

news....news....news

PMLD-Link WEBSITE

PMLD-Link has its own website! This has been designed by Kevin Smart and the information is intended to give up-to-date details of the current issue, how to subscribe, list the topics covered in recent years, and links with other useful organisations.

You can find PMLD-Llink on http://www.pmld-link.co.uk

MENCAP'S TRANSACTIVE PROJECT WINS TOP AWARD

Mencap's Trans-active, a pioneering multimedia blueprint for teenagers with learning disabilities exploring post-school options, has just been announced winner of the Guardian/Institute for Public Policy Research 'e-involvement' award, supported by the Improvement and Development Agency.

Laura Edwards, senior research fellow at ippr, said: "Mencap's Trans-active project uses technology not for its own sake but as a way of giving young people with learning disabilities a more powerful voice in transition meetings. Traditionally, these meetings have not been structured in a way that enables young people to participate at all."

Claire Brown, Mencap's Trans-active Project Manager, said: "Winning the award has been a fantastic achievement for all the Trans-active team, UEL team, participating schools and particularly the 80 young people who have taken part so far. The project has allowed all these groups to work together in a person-centred way to improve life choices for young people. The award also recognises the innovative partnership between Mencap and UEL, allowing the expertise of a first-class multimedia team to develop usable tools for young people with a learning disability."

Andy Minnion, Director of the Multimedia and Learning Disability Research Project at UEL said: "We are delighted that Trans-active is having such a tremendous impact. Multimedia may still be a bit of a mystery to most adults, but for teenagers of all abilities it provides an accessible and enjoyable communication tool that can help empower those with learning disabilities."

Trans-active – passport to a better future

Trans-active was set up by national learning disability charity Mencap and funded by The Diana, Princess of Wales Memorial Fund. It is run in collaboration with the University of East London and is a key focus for the work of the Multimedia and Learning Disability Research Project based at UEL's Docklands Campus.

Mencap's Trans-active project enables young people with severe or complex learning disabilities to play an active role in the important 'transition' planning process that starts when they are 14 and 15 - with discussion about their future plans and a range of issues including job opportunities, education and housing.

Young people with a learning disability are paired with peer supporters, who are trained in disability awareness, sign language and advocacy skills. Over a school year they work together in joint sessions, at a residential weekend and on project visits. Together they create a multimedia CD

Rom 'passport' that captures each student's life and future wishes. This can then be used in transition meetings to ensure that each young person has their say in decision-making.

Tools for Transition Conference – Trans-active and lots more

Trans-active will be launched nationally at a Conference: ***Tools for Transition*** next spring.

The Conference will take place on Wednesday, 19 March 2003 at The Think Tank in Birmingham. It is designed for all professionals working with teenagers with and without learning disabilities in education, Connexions (careers), youth, health and social services. Young people with learning disabilities and their parents are also invited.

Stephen Twigg, Parliamentary Under-Secretary for Young People and Learning, will open the Conference. It will be a unique opportunity to find out first-hand how Trans-active works and meet the young people with severe disabilities who piloted Trans-active. Delegates will be able to test drive the new Transition Tools on the spot, with Trans-active experts there to guide and advise them.

Claire Brown, Mencap's Trans-active Project Manager, said: "Trans-active gives teenagers with learning disabilities the chance to explore their future options – such as lifelong learning, living arrangements, leisure pursuits and employment – as never before. Support from mainstream peers opens up their choices. They get the chance to see the bigger picture and aim higher than they might otherwise have done."

"This Conference puts the full spotlight on transition and communication issues, asking important questions and giving some exciting answers. We guarantee delegates will walk away inspired, with tasters of best practice solutions and models to implement in their own area."

Discussion topics include 'The transition challenge – are *you* ready to take it'" led by Robina Mallet from Home Farm Trust and Linda Ward from Norah Fry Research Centre. In 'Let's work this out!', Chris Sholl from the NHS and the Valuing People team discusses multi-agency models that meet the person-centred challenge.

The day also features interactive sessions, such as 'How to survive as a teenager' and 'Speaking up, speaking out!', as well as Interaction – a marketplace for hands-on experience of multimedia and information and communication (ICT) tools to empower young people and their supporters.

Tickets to the Conference (which includes a sandwich lunch) cost £85 each for professionals. ***Young people with learning disabilities and their parents are invited along for free***.

For a Trans-active Conference Application Form, contact Claire Brown, Mencap's Trans-active Project Manager, on 0121-707 7877 or write to her at Mencap, 4, Swan Courtyard, Coventry Road, Birmingham B26 1BU or e-mail her on: claire.brown@mencap.org.uk

For further information about the project, visit www.trans-active.org.uk

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UNNOTICED OR UNTREATED

Up to 40% of young people with learning disabilities experience mental health problems, yet they regularly go unnoticed or untreated. These are the findings of a year-long inquiry by the Foundation for People with Learning Disabilities, published in December 2002.

The Inquiry into Meeting the Mental Health Needs of Young People with Learning Disabilities heard evidence from more than 250 people. It found that young people with learning disabilities are twice as likely to develop mental health problems as other young people, yet many families struggle for years to get appropriate help.

Dr Andrew McCulloch, Chief Executive of the Foundation for People with Learning Disabilities said:

> *"Young people with learning disabilities are susceptible to bullying, abuse, social exclusion and low self-esteem. Many live below the poverty line. These factors alone mean they're likely to develop treatable mental health problems, yet time and again, we've heard from them and their families that they're not getting the support and treatment they need."*

We have to ask, "Why?" Is it because, as one parent suggested, we see the disability first and the person second? Mental health problems such as depression and anxiety are often wrongly perceived to be part of the disability. Why should young people with learning disabilities put up with mental health problems when the rest of the population rightly expects treatment?

> *"We have uncovered a vicious circle. The low self-esteem that often hits adolescents with learning disabilities is largely caused by negative attitudes in our society. Yet these are the very attitudes that mean resulting mental health problems go untreated."*

The Foundation for People with Learning Disabilities is calling on health, education and social care policy makers to recognise that learning disabilities and mental health problems co-exist, and to provide services accordingly.

Reports of young people with learning disabilities waiting three years for a referral to a psychologist, or of their being over-medicated for want of any other suitable treatments have prompted the calls.

Dr McCulloch said:

> *"Services in many areas are planned for a world where you can have either a learning disability or a mental health problem, but not both. It's time for this to end."*

Further information can be obtained from:
Celia Richardson, The Foundation for People for Learning Disabilities, Tel: 020 7802 0312 or, out of hours, Tel: 07721 587643; email crichardson@mhf.org.uk

the
Foundation for People
with Learning Disabilities

Renting Your Own Home
Written by Maurice Harker and Nigel King,
Housing Options
Published by BILD

This is an excellent resource for any parent or carer who is considering housing options for people with learning disabilities. It is very clearly written informative and easy to follow.

The first section of the booklet sets the historical background and legalisation which underpins local authorities' duty to provide housing care and support. When set out in such a clear and comprehensive manner one can be left in no doubt about the obligations which a local authority has towards the care of our children and adults with learning difficulties.

It has been Government policy since the White Paper of 1989 '*Caring for people*' to support independence as far as possible, the core principle being to enable people to live as normal a life as possible in their own homes or in a homely environment in the community.

As a parent I have heard many stories about the failings of care in the community but when properly resourced and managed there is often a very different story of lives being lived fulfilled in every sense of the word. The problem for parents and carers is that they are very often not aware of their rights and whilst many may choose for their children with learning disabilities to continue to live at home with them well into adult life, many are not aware that there are other options available. For this reason alone this publication is particularly welcome.

The government brought in the direct payments act in 1996 which means that local authorities can make direct payments for their care and support leaving greater freedom to arrange their own package of care. The guide tells us that this has not been widely adopted by local authorities as yet but the Government intends to make it compulsory for all local authorities to offer this service.

People with learning disabilities no longer have to face the choice of home or away. There are now various support options which have been tried and tested as an alternative to residential care.

The writers of the booklet suggests that through their own research for the publication they have found evidence that, not only do these different support options promote a greater degree of independence, it is also thought that they match resources more precisely to individual needs.

The following sections of the guide take the reader through the process of renting housing and the cash benefits which are available for people who choose to live in their own home even though they may have significant care and support needs.

Further sections spell out the different type of tenancies which are available, the complexities of registration qualifications for care homes and the options of renting a property form parents or succeeding to a tenancy.

This is a most welcome publication which should be made available to all who are pondering the questions, "Where do we start?" and "What are the choices available for my son or daughter's future"?

Julia Dixon
Parent
PMLD-Link Editorial Team

Shared ownership
Written by Tony Dixon
Advance Housing and Support
Published by BILD

This booklet is a comprehensive guide to shared ownership and promotes it as a viable option for people with learning disabilities who wish to own their own home.

The guide explains very carefully what the term means and how it can enable people with learning disabilities to obtain a mortgage in order to buy a 50% share of the property initially and rent the other 50% from a housing association moving towards gradually increasing the share owned by the tenant.

The whole process of funding such a project is explained and supported by detailed examples taking the reader through the complexities of meeting a mortgage payment through income support and housing benefit payments. This do it yourself guide reminds us of the start up costs, those hidden extras such as solicitiors' fees and stamp duty which are easily overlooked, but the examples used take account of these costs and offer suggestions of how these expenses may be met.

The author goes on in following sections to explain how to apply for shared ownerships commencing with advice on how to look for suitable properties including advice on the benefits of commissioning a surveyor to inspect and survey potential properties to safe guard the investment for the shared owner and the housing association.

Buying a property and moving house is reputed to be one of the most stress inducing life events, however the author takes us gently through a staged process of applying for a mortgage and finding a solicitor and the role which the housing association plays in the process of helping people with learning disabilities to own their own home.

Its comforting to know that the help does not cease at the point of ownership, ongoing help and support is available through a leasehold management service providing a comprehensive package of liaison dealing readily with any issues related to the lease and the home.

The booklet provides addresses for further information from 'Advanced Housing' and 'Housing Options' at the back of the book.

This is an excellent publication and will be very helpful to anyone choosing to realise their dream of owning their own home.

Julia Dixon
Parent
PMLD-Link Editorial Team

Teaching Pupils with severe and Complex Difficulties: Back to First Principles
by Christopher Dyer published by : Jessica Kingsley Publishers 2001
ISBN 1 85302 951 3

This book held so much promise. An author with enormous experience in the field, well able to reflect upon the dramatic changes in the field of special education. A book nominated for the TES/NASEN Special Needs Academic Book of the Year award, so presumably commended by a learned group of educationalists. Sadly, this promise was unfulfilled.

Dyer's call to 'first principles' is welcome. In recent years the politically driven curriculum agenda in education, has failed to focus sufficiently on pedagogy and how children learn. Thus to integrate theories and approaches in these areas within a now established (and recently revised) curriculum framework is timely. However, scant attention is paid to the legislative educational framework teachers of pupils with severe and complex learning needs will find themselves operating within.

There are key chapters on language, thinking and behaviour, to which Dyer applies his principles of natural education. He considers 'principal principles', which he maintains, "need to underpin both curriculum planning in the broad view and classroom practice in the particular view to ensure the effective educational advance of each pupil" (p.11). Yet these principles are articulated, and verified through, at times, abstract philosophical debate and concepts which will not hold relevance for many classroom practitioners.

Indeed Chapter 3 is headed 'Detective Stories'; the ensuing investigation is conceptualised as a forensic puzzle, and observation is the key strategy for gaining clues. Whilst observation is essential in the repertoire of teaching strategies, the descriptions in this chapter would leave many clueless!

There are fundamental problems with this text which make it impossible to commend to others. Its structure and viewpoint are 'avant garde' to the extent that they become incomprehensible. Also there is an over-reliance on child development texts which rehearse typical development, but do not give insight with untypical development. The approach taken throughout is one of attempting to understand the child from the 'inside out'. This may, unfortunately, lead some to a deficit-model of understanding 'severe difficulties in learning'.

The special education texts used to support Dyer's arguments are at times, dated. Some (e.g. Tansley & Gulliford, 1960; Brennan 1985) would be classed as seminal, and worthy of mention in an historical overview. However, the total absence of reference to authors such as Byers, Tilstone or Rose, all of whom have written extensively on the teaching and learning of children with severe learning difficulties, is, frankly, disrespectful to the magnificent insights these authors have given us.

Christopher Dyer's vision of reviving the debate on the first principles which should inform the teaching of pupils with severe and complex difficulties is sound. Sadly the reality is disappointing, and fails to live up to the promise of the book's title.

Professor Barry Carpenter OBE
Chief Executive
Sunfield School

BOOKS AND RESOURCES

Renting Your Own Home written by Maurice Harker and Nigel King. Published by BILD. A resource for any parent or carer who is considering housing options for people with learning disabilities. Reviewed in this issue.

Shared ownership written by Tony Dixon. Published by BILD. A guide to shared ownership for people with learning disabilities who wish to own their own home. Reviewed in this issue.

Teaching Pupils with severe and Complex Difficulties: Back to First Principles written by Christopher Dyer and published by Jessica Kingsley Publishers 2001. A debate on the first principles in the teaching and learning of children with severe and complex difficulties. Reviewed in this issue. ISBN 1 85302 951 3

Promoting Inclusive Practice written by Christina Tilstone, Lani Florian and Richard Rose. Published by Routledge 2003. Current developments in thinking and practice in supporting the process of inclusion.

Celebration – a free booklet produced for National Poetry Day 2002 by the National Poetry Society and the Forward Poetry Trust for teachers of pupils with special needs. A selection of poems with ideas for activities to use with students with an introduction by Nicola Grove and Keith Park. Available free from the Poetry Society, 0207 420 9892.

Playing, Laughing and Learning with Children on the Autism Spectrum. A Practical resource of Play Ideas for Parents and Carers written by Julia Moor and published by Jessica Kingsley Publishers 2002.

Towards a Curriculum for all: A practical guide for developing an inclusive curriculum for pupils attaining significantly below age-related expectations produced by the Dorchester Curriculum Group and published by David Fulton Publishers. A holistic approach to the development of a curriculum relevant for pupils and students with profound and multiple learning difficulties. ISBN 1 85346 773 1

All Together (2nd Edition) written by Mary Dickins and Judy Denziloe, published by the National Early Years Network, 2002. ISBN: 1870085621

Brothers and Sisters – how to help the siblings of very sick and disabled children. A booklet for families written and published by Sarah Barrell. ISBN 0 9542871 0. Available from Sarah Barrell, PO Box 95, Witney, Oxfordshire OX29 4WJ.

Journey to Independence: How to run your life with direct payments written by Stacey Gramlich, Gordon McBride, Natasha Snelham, with Ken simons and Val Williams. Resource for self advocacy groups and people with learning disabilities – how to get direct payment and find and employ a personal assistant. BILD Publications, Plymbridge Distributors, Estover Road, Plymouth, PL6 7PZ. Tel: 01752 202301.

Easy Guide to the Human Rights Act 1998 written by Andrea Hughes and Phil Coombs. An outline of the key elements of the Act and how they can be applied to protect the legal rights of people with learning disabilities. Examples and suggestions for good practice. Published by BILD.

See What I Mean: Guidelines to Aid Understanding of Communication by People with Severe and Profound Learning Disabilties written by Nicola Grove. Guidelines to help staff understand what people with severe and profound learning disabilities are communicating, particularly in the context of decision making. Published by BILD/Mencap 2000. ISBN 1 902519 41 8

VIDEOS

Twinkle Soundabout: a 15 minute video produced by RNIB 2002. A musical simulation video of a journey through the galaxies. Sound, Silence, Light and colour are integrated into high quality visual graphics.

MISCELLANEOUS

Wearability – provides clothing to suit individuals' dressing needs, from underwear to wheelchair capes. WEARability, BFSDP, Unit 7, Canalside Workshops, Leverton Road, Retford, Notts DN22 0DR. 01777 860206 or postmaster@bfsdp.free-online.co.uk or www.bfsdp.free-online.co.uk.

COURSES AND CONFERENCES

FEBRUARY

3rd BILD Conference
Quality: A person centred approach
Organised by: BILD
Venue: Hilton Hotel, Warwick
Further details: Liz Howells
Tel: 01562 723025
e-mail: l.howells@bild.org.uk

12th Come on in!
Conference to launch the Report on a project looking at examples of good practice in inclusive leisure schemes with speakers and workshops exploring the issues raised.
Organised by: Action for Leisure
Venue: Paragon Hotel, Birmingham
Further details: Action for Leisure
Tel: 01926 650195

14th Overview of the BILD Physical Inverventions Programme
Introduction to the Physical Interventions Scheme and refresher for people who have used elements of the scheme in the past. Sessions will cover historical development; policy framework; overview of the Code of Practice; future developments.
Organised by: BILD
Led by: Sharon Powell or an experienced facilitator
Venue: Worcestershire
Further details: BILD
Tel: 01562 7223029
e-mail: z.tibbetts@bild.org.uk

28th Sherborne Developmental Movement – Level 2
1 day course for those who have already attended a Level 1 course.
Organised by: Sunfield Professional Development Centre
Led by: Cyndi Hill and George Hill
Venue: Sunfield PDC, Clent
Further details: Sunfield Professional Development Centre
Tel: 01562 883183
e-mail: sunfield@sunfield.worcs.sch.uk

MARCH

5th Mums the Word II
The first in a series of family training days. A chance for mums to meet and share experiences, relax, unwind and try out a range of alternative therapies.
Organised by: Sunfield Professional Development Centre
Venue: Sunfield PDC, Clent
Further details: Sunfield Professional Development Centre
Tel: 01562 883183
e-mail: sunfield@sunfield.worcs.sch.uk

11th Working with Parents
Organised by: London University Institue of Education
Led by: Dr. Dawn Male
Further details: Linda Richards
Tel: 0207 612 6271

13th BILD Conference - Valuing Good Practice in Autism

Conference to disseminate good practice and facilitate a reflective and evaluative approach. Keynote speakers and workshop sessions which cover a range of key issues for those involved with autistic spectrum disorders.

Organised by: BILD
Venue: East Midlands Conference Centre, Nottingham
Further details Liz Howells
Tel: 01562 723025
e-mail: l.howells@bild.org.uk

13th Multi-sensory Approaches to Learning and Life

Organised by: Sunfield Professional Development Centre
Led by: Flo Longhorn
Venue: Sunfield PDC, Clent
Further details: Sunfield Professional Development Centre
Tel: 01562 883183
e-mail: sunfield@sunfield.worcs.sch.uk

25th Overview of the BILD Physical Inverventions Programme

Introduction to the Physical Interventions Scheme and refresher for people who have used elements of the scheme in the past. Sessions will cover historical development; policy framework; overview of the Code of Practice; future developments.

Organised by: BILD
Led by: Sharon Powell or an experienced facilitator
Venue: Dublin
Further details: BILD
Tel: 01562 7223029
e-mail: z.tibbetts@bild.org.uk

26th Overview of the BILD Physical Inverventions Programme

Introduction to the Physical Interventions Scheme and refresher for people who have used elements of the scheme in the past. Sessions will cover historical development; policy framework; overview of the Code of Practice; future developments.

Organised by: BILD
Led by: Sharon Powell or an experienced facilitator
Venue: Belfast
Further details: BILD
Tel: 01562 7223029
e-mail: z.tibbetts@bild.org.uk

26th Playwork Inclusion Project Regional Seminar

Including disabled children in play and out of school settings

Organised by: Playwork Inclusion Project with
Early Years and Development Childcare Partnership
Venue: Torquay
Further details: Philip Douch
01453 752509
Philip.douch@majestique.co.uk
Jacqui Byland
0120 459 8213

28th A Master Class on English and Mathematics for Learners with Profound and Multiple Learning Disibility

Organised by: Catalyst Education
Led by: Les Staves and Flo Longhorn
Venue: Central London
Further details: Tel: 0845 127 5281

APRIL

1st A Master Class on English and Mathematics for Learners with Profound and Multiple Learning Disibility
Organised by: Catalyst Education
Led by: Les Staves and Flo Longhorn
Venue: Manchester University
Further details: Tel: 0845 127 5281

3rd Finding ways to Develop Relationships with pupils with ASD

Ways to get in touch with your children and clients, to understand their personal language and give you confidence and skills to develop positive relationships.

Organised by: Sunfield Professional Development Centre
Venue: Sunfield PDC, Clent
Further details: Sunfield Professional Development Centre
Tel: 01562 883183
e-mail: sunfield@sunfield.worcs.sch.uk

MAY

2nd Second annual Catalyst Conference onEducating Pupils and Students with Severe, Profound Multiple Disabilties: the best in innovation, research and good practice
Venue: University of London Institute of Education
Further details: 0845 127 5281

9th The Education and Lives of Teenagers and Young Adults with PMLD

Two day workshop

Organised by: Catalyst Education
Led by: Flo Longhorn
Further details: Flo Lonhorn
e-mail: FloCatalyst@aol.com

13th to 15th NAIDEX
Venue: NEC, Birmingham
Further Details: Emap Healthcare Events
0207 874 0294
www.naidex.co.uk

17th A Home of their Own

The second in a series of family training days. A day for dads only to come together. Planning the housing element of future life plans for young people with special educational needs – the professional and personal perspective. Workshops on the emotional and practical challenge for fathers.

Organised by: Sunfield Professional Development Centre
Venue: Sunfield PDC, Clent
Further details: Sunfield Professional Development Centre
Tel: 01562 883183
e-mail: sunfield@sunfield.worcs.sch.uk

JUNE

7th A Siblings Fun Day

The third in a series of family training days. A day for siblings of children with special needs aged between 6-13 years. A variety of events in and around Sunfield.

Organised by: Sunfield Professional Development Centre
Venue: Sunfield PDC, Clent
Further details: Sunfield Professional Development Centre
Tel: 01562 883183
e-mail: sunfield@sunfield.worcs.sch.uk

10th to 12th Sherbone Developmental Movement - Level 3
Three day residential course
Organised by: Sunfield Professional Development Centre
Venue: Sunfield PDC, Stourbridge
Further details: Administration Office, CPDC
Tel: 01562 883183
e-mail: sunfield@sunfield.worcs.sch.uk

18th Environmental Wealth: Using the environment to promote teaching and learning
For practitioners supporting children and young people with sensory impairment and additional needs.
Venue: University of Birmiingham
Further details: Noreen Stacey
Tel: 0121 414 3294
e-mail: N.M.Stacey@bham.ac.uk

24th Facilitating Friendships
One day course
Organised by: London University Institute of Education
Led by: Dr. Dawn Male
Further details: Linda Richards
Tel: 0207 612 6271

NOVEMBER

13th Education and Leisure for Teenagers and Young Adults with Profound Disability
Two day training conference.
Organised by: Catalyst Education
Venue: Queen Alexandra College, Birmingham
Further details: Tel: 0845 127 5281

19th 'Supporters Club'
The last in a series of family training days for grandparents, adult siblings, aunts, uncles, friends and neighbvours. A chance to meet together and discuss common issues.
Organised by: Sunfield Professional Development Centre
Venue: Sunfield PDC, Clent
Further details: Sunfield Professional Development Centre
Tel: 01562 883183
e-mail: sunfield@sunfield.worcs.sch.uk

BILD Workshops and Conferences

These cover a wide range of topics including:

- Understanding Autism
- Understanding Challenging Behaviour
- Sexuality and Personal Relationships
- Exploring Creative Ways of Working
- Mental Health
- Communication Through Drama
- Physical Interventions - Code of Practice
- Developing policies in management of challenging behaviour
- Person Centred Planning
- Putting the Learning Disability Awards Framework into Practice
- Life Story Work
- Risk Assessment Management

All these courses are held several times throughout the year in different parts of the country. For the schedule and further details contact Liz Howells 01562 723025; e-mail l.howells@bild.org.uk

Advocacy Tour 2003

Citizen Advocacy meetings in a number of venues. The Valuing People Support team will be at each meeting to talk about different types of Advocacy, and advocacy in your area.

11th February	Cambridge
18th February	Exeter
19th February	London
25th February	Durham
26th February	Leeds

Further details: BILD
Tel: 01562 723027

LONGER COURSES *(with accreditation)*

Interdisciplinary work with People with Profound and Multiple Learning Disabilities

A one year distance education course for practitioners and carers of children and adults with profound and multiple learning disabilities. The main focus is upon lifelong learning, communication and effective interdisciplinary collaboration.
Offered at three levels: Post experience certificate (level 1), Advanced Certificate (level 3), Post graduate diploma and Masters (level M)
University of Birmingham School of Education
Further details: 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
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.
University of Manchester Faculty of Education
Further details: The Programme Secretary, Educational Support & Inclusion
JTI Office, University of Manchester, Oxford Road, Manchester M13 9PL
Tel. 0161 275 3337
e-mail: JTI Office@man.ac.uk

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. Each student is supported by a tutor throughout the course.
Further details: BILD Learning Services
Tel. 01562 723010

Certificate in working with people who have learning disabilities: Your Pathway to Achievement

Course programme and supporting materials developed by The Foundation for People with Learning Disabilities, Tizard Centre (University of Kent) and Pavilion Publishing. Trainer's toolkit and student workbook enable students to achieve qualifications through the learning disabilities award framework.
Available from Pavilion Publishing – Tel: 01273 623222 or e-mail: info@pavpub.com.