

PMILD**LINK**

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

CONTENTS

Editorial	Carol Ouvry	1
Future Focus	Beverley Dawkins	2
Contact a Family		3
Mencap	Beverley Dawkins	4
In Touch	Ann Worthington	5
Norah Fry Research Centre Can Adults who do not use words have control over their own lives?	Val Williams and Ken Simons with Swindon People First	7
No Ordinary Life	Julia Dixon	12
Opportunities for Physical Activities for Adults with Profound and Multiple Disabilities - a new scheme	Connie Williams	17
'Community Contacts' for People with Profound and Multiple Learning Difficulties: some Ghanaian perspectives	Mawutor Avoke	18
Facilitating Affective Engagement with Children with Autism through the Medium of Colour	Diana Pauli and Melanie Smart	21
Report Back		
Communication and PMLD - Assessment and Beyond		25
Objects of Reference: their role in supporting learners with multiple disabilities		26
What makes the Difference? Linking Parents and Professionals: meeting the needs of people with profound and multiple learning disabilities		27
News		29
Reviews		32
Publications and Resources		33
Inservice Training		
Courses and Conferences		34
Open Days		36
Long Courses (with accreditation)		36

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

EDITORIAL

The focus for this issue is on organizations with a specific brief for PMLD or which significantly include PMLD issues in their services or research. There are, of course, many such organizations, either national or local, across the country. Those which have contributed information to this issue are well known, and all, or some, will be familiar to most of our readers. But you may not know exactly what their working brief is, what services they can offer, or what current or recent research they have carried out. I hope these articles will fill you in and also alert you to other organizations and developments to keep track of, such as the new PMLD-Network, and the Birth Defects Foundation which is taking over many of the functions of IN TOUCH.

I hope to bring you information about other organizations in future issues, and if there is a service in your area which you think would be of interest to readers or those trying to set up their own local services, please let me know so that I can contact them for more information.

As usual there are also articles on other topics - as varied as community links in Ghana; a follow up of a previous article on the use of colour therapy with people with autism with many interesting observations which may have relevance for people with PMLD; and a paper given at the MENCAP/PMLD-Link joint seminar which is an interesting and open commentary on the implications of having a family member with PMLD and the services, bad and good received by this particular family.

A number of articles touch upon the topic for the next issue, introduced in FUTURE FOCUS - Involving people with PMLD and the issues of representation and consultation. Do you have any experiences to share with other readers? If so, do write in.

Business Matters

This is the second issue of this subscription year. With the final issue (probably early in the new year) you will be sent a separate subscription form and you will then need to renew. For those of you who have only recently sent in their subscriptions for the year 2002 it will seem very soon to be having to renew - so be prepared!

Articles on any topic for inclusion in the next issue should reach me by 30th November. Send by post or e-mail (Rich Text Format please) to the address below and if you have any diagrams or pictures could you please send a hard copy as my machine seems to have great difficulty in decoding them. A diagram in text format is no good at all I have discovered!

**Carol Ouvry
PMLD-Link
The Old Rectory
Hope Mansell
Ross-on-Wye
Herefordshire HR9 5TL**

**Tel: 01989 750382
e-mail: PMLD@mansell.wyenet.co.uk**

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

FUTURE FOCUS - Involving People with Profound and Multiple Learning Disability - Representation and Consultation

In the recent publication '*Valuing People with Profound and multiple Learning Disability*' we wrote "The advocacy movement has done much to enable people with a learning disability to take their rightful place in society, but people with PMLD have had little part of this. As a result of this, people with PMLD are disadvantaged across the whole spectrum of service provision. We need to address the issue of meaningful representation" (PMLD Network 2002).

This represents quite a challenge. We have come a long way in our understanding of the communication needs of children and adults with PMLD. We know that many individuals are not able to use formal means of communication such as speech, signs and symbols or are able to make use of communication technology. Rather, that they may rely on the ability of those around them to interpret their use of vocal sounds, facial expression and body language for example. Whilst we have increased participation in day to day choice making, such as around food and daily activities, it is somewhat harder to involve people in the bigger decisions such as where and with whom they live. It is harder still to involve them in, for example, a consultation about what they think of the day service they currently attend.

So, the focus for the next edition of PMLD-Link is about the ideas you have about how we translate that knowledge about communication into actions that really enable people to participate in the decisions that affect their lives. This is an issue that is very current in a climate where there is a great emphasis on service user involvement and we are sure that many of you may be developing ideas or projects along these lines. Perhaps you are involved in a citizen advocacy service, a circle of support or have developed a service user forum. Perhaps there is a current consultation going on in your area and you have done something to ensure that the needs of children or adults with PMLD have been represented. We look forward to hearing your ideas.

Beverley Dawkins

*National Officer for Profound and Multiple Learning Disability
Mencap*

CONTACT A FAMILY

Every day over 75 children in the UK are born or diagnosed with a serious disability. There are around half a million disabled children and young people in the UK. Discovering that your child has a special need or disability is always very difficult. The feeling of isolation can often be acute. For over 21 years, Contact a Family has been working to support and inform families regardless of the medical condition of the child.

Families tell us that their greatest need is for information. This includes information about entitlements to support and provision for special educational needs. And, perhaps more importantly for those with a child only recently diagnosed with a rare condition, families are often desperate for accessible medical information and some contact with families in a similar situation so they can share experiences and benefit from the mutual support this contact can bring.

Our team of experienced advisers can:

- put families in touch with support groups or, where there isn't a group, as is the case with many very rare disorders, try to link families directly on a one-to-one basis;
- put families in touch with any other specialist voluntary organisations which may be able to help;
- give medical information on all conditions affecting children and young people;
- advise on services like respite and your rights to benefits and any other help which may be available;
- send you any one of our range of factsheets on subjects such as living without a diagnosis, grandparents, siblings as well as practical information about your rights to education and benefits;
- talk to you via an interpreter in over 100 languages if you prefer to use a language other than English;

Contact a Family also campaigns to raise awareness. We are currently encouraging more families to claim Disability Living Allowance for their children, as we estimate that only half of families claim this. This can be paid if your child needs more help with personal care or more supervision than a non-disabled child of the same age, or if your child has mobility problems. Do call us to see if you are entitled.

We are currently involved in a research project to look at the needs of families with more than one disabled child, focusing particularly on the financial costs. If you have more than one disabled child and might like to take part, please do get in touch with us to find out more about it.

To get in touch, you can:

Phone our National Freephone Helpline Tel: 0808 808 3555 (10am-4pm, Monday to Friday). The service is free and confidential.

If you use a minicom you can contact us on 020 7608 8702.

Or you can e-mail us - helpline@cafamily.org.uk.

Or you can write to us at 209-211 City Road, London, EC1V 1JN.

Our website www.cafamily.org.uk also has lots of useful information and contains our directory of rare conditions and syndromes affecting children.

MENCAP

The role of National Officer for Profound and Multiple Learning Disability (PMLD).

Mencap's National Officer for PMLD has a national brief, specifically in support of children and adults with profound and multiple learning disabilities and their parents and carers.

The National Officer's work includes:

- Campaigning for more quality services and opportunities within education, social services, health and leisure, and for individuals with PMLD to have equal access in all aspects of their lives. Some recent projects are:

'Don't Count Me Out' (Mencap 2001) aimed at improving support to disabled children with continuing health needs in school.

'No Ordinary Life' (Mencap 2001) on the experiences of families caring for a son or daughter with PMLD, and their need for much greater support.

'Valuing People with Profound and Multiple Learning Disability' (PMLD Network 2002) aimed at increasing understanding of the needs of children and adults with PMLD when implementing the White Paper, *'Valuing People'*.

- Working in partnership with parents and professionals to raise awareness of the needs of individuals with profound and multiple learning disabilities and their families and carers and supporting developments by providing awareness training sessions both within Mencap and beyond at a local, regional and national level.
- Promoting and developing examples of good practice. Examples of current projects include developing user involvement and representation through the use of Multi Media Profiling and the Holiday Project where we are working with a holiday provider to increase their capacity to offer high quality holidays to families or individuals.
- Networking on a national basis with other agencies and professionals. The National Officer represents Mencap on various working parties and advisory groups. A PMLD Network is being developed to bring together all those with an interest in PMLD to share good practice and campaign on relevant issues.
- Provision of specialist information and advice on all aspects of multiple disability. This can be about almost anything but typical examples include helping staff and parents access appropriate training and offering support to families who are experiencing difficulty getting access to the services they need.
- Seminars, presentations and training. A National Focus Group comprising of a small group of parents and multi-disciplinary professionals assist the National Officer in organising a series of seminars and 'round table discussions' centred on different themes. The most recent of these was jointly run by Mencap and PMLD-Link and looked at parent and professional relationships. In addition the National Officer is asked to provide presentations at a variety of training and conference events.

Beverley Dawkins

Mencap National Officer (PMLD)
London EC1Y 0RT

Telephone: 0207 696 5558

Internet: e-mail: beverley.dawkins@mencap.co.uk

World Wide Web: <http://www.mencap.org.uk>

IN TOUCH

IN TOUCH was set up in March 1968, with the aim of linking up parents with others whose child had a similar disability or presented the same day to day problems. It was intended to be nothing more than an additional outlet, enabling parents to exchange support, ideas and experiences or to talk about their feelings whenever they felt the need. I was amazed by the immediate and enthusiastic response from parents all over the country to what I felt was a very simple idea. My first reaction bordered on panic but, once I got down to answering the letters, I found that I was able to provide each parent with two or three appropriate addresses. I did not expect them all to keep in touch with me, but found that most of them did - telling me about their child's progress or special problems, or giving me information which might be of use to others. The next logical step was to provide a newsletter containing all this 'feedback'. The first newsletter covered one page and went out to about a hundred people.

From that point on, In Touch grew, without any particular attempt on my part to publicise it. The newsletters increased in size and before too long, around a thousand newsletters, of up to 40 A5 pages, were going out three times a year. The growing involvement of professionals in all aspects of childhood disability was a surprising development. About a third of the membership was made up of doctors, health visitors, social workers, psychologists and therapists, seeking information for the benefit of children in their care. Even more surprising, however, is the way in which In Touch quickly became established as a national contacts and information service for rare disorders. Naturally, when a parent presented me with an uncommon disorder which someone had asked about previously, I would put them in touch with one another (always taking great care that the match would be beneficial to both parties).

Over the years, I have been presented with a very wide range of disorders and, as a result, have built up a large bank of reference material. It is unlikely that a parent whose child has a very rare condition will meet anyone in their own area, but because In Touch goes into many hospitals, local authority departments and other establishments where staff are dealing with all types of special needs, the 'network' was very effective in finding contacts for even the most obscure of conditions. It was very gratifying to see national support groups emerging from groups of people linked up through In Touch; several started in this way, including the Tuberous Sclerosis Association, the Prader-Willi Association, the Wolf Syndrome Contact Group and a number of others. New groups are now being set up all the time, usually by parents whose children are affected by very rare conditions.

For the first fifteen years, In Touch was run single handed. However, it became apparent that it could no longer be regarded as a spare time activity. It became a constant struggle to finance it myself and to cope with the relentless stream of enquiries which came in day by day. In 1982, In Touch was registered as a charity and, subsequently, I managed to get funding from the Department of Health which covered part of the running costs for a three year period. Later, the Trust was fortunate to be granted funding which allowed me a modest salary as full time organiser and for some part time assistance. I have had the invaluable help of a part time secretary for the last fifteen years. Continued funding was always a problem and we have often been very close to having to wind up the service. But, we managed to keep going for almost thirty four years, thanks to grants from bodies such as Children In Need, Mencap City Foundation, Marks and Spencer and other grant-making trusts.

The continuous contact with thousands of families over the years has provided me with a wealth of material which is invaluable to parents of newly diagnosed children. This provided the material for my book *Coming to Terms with Mental Handicap* which was published in 1982. Because of the many changes in the special needs field, this book requires updating, so is not available at present.

We were getting more and more requests from professionals for printed information about rare disorders. We had information available but much of the terminology used to describe the separate features found in rare syndromes was not readily understood by lay readers. So, after about a year's research I produced my third book *Glossary of Syndromes Associated with Learning Difficulty* which has now been reprinted three times and is widely used by people in all areas of the special needs field.

In 1999, I was commissioned to edit a book being published by David Fulton Publishers: *The Fulton Special Education Digest*. This 4000 page book contains details of around 1000 selected organisations, charities and services that exist to help the child with special needs, a listing of special schools in the UK and information about how to find out more about inclusive schooling in particular regions, articles on current policies and topical issues in special educational needs, a glossary of terms most commonly associated with special education, syndromes and disorders, details of major exhibitions and events, an explanation of the bewildering variety of acronyms commonly used in special education and pointers to resources on the Internet. The second edition of the *Digest* is about to be published.

In Touch started out as a service catering for learning disability but, over the years, it expanded to include all types of special needs in children; learning disability, physical disability and multiple disability. In some ways, the service was very different from the simple contact scheme set up in 1968. But, I was always keen to maintain an informal approach, dealing with all enquiries in a sensitive but practical manner. I found myself at the centre of a huge network of parents and professionals in the UK and many overseas countries, willing to offer help to anyone who could benefit from their experience.

Update

Over the last few years, it has become increasingly difficult to obtain funding to enable In Touch to carry on. The last two years in particular, have been a constant struggle financially and so I have been forced to make the decision to wind up the service and dissolve the charity. However, we have been given a Department of Health grant which will allow us to provide a reduced service until April 2003, when the official winding up of the charity will be carried out. Because In Touch is listed in databases and resource banks all over the UK we will receive requests for support and information for some time to come, so we will continue to provide an information service for the time being. We will be unable to produce our thrice-yearly In Touch newsletter.

However, the news is not all bad. We will be joining forces with the Birth Defects Foundation and all enquiries concerning special needs in children will be dealt with by the BDF staff of trained nurses and/or by myself. We will also be producing a newsletter, very similar to the In Touch newsletter, which will appear on the BDF website. Some hard copies of the newsletter will be available to those who do not have access to the Internet.

People calling the normal In Touch line will be referred on to the BDF panel of experienced nurses, who will be able to provide a 'listening ear' and to provide any practical information, such as details of support groups and sources of help and advice on all aspects of special needs in children. If anyone has a particular need to speak to me personally, BDF will pass on their message to me and I will contact them as soon as I am able.

This amalgamation with BDF will enable me to continue to work with and for parents of children with special needs, albeit in a slightly different way. I hope that it will provide parents with a comprehensive service and sympathetic support.

Ann Worthington MBE

10 Norman Road
Sale
Cheshire M33 3DF
Tel: 0161 905 2440

NORAH FRY RESEARCH CENTRE

Norah Fry Research Centre at the University of Bristol carries out research into issues affecting the lives of disabled children and adults with learning difficulties, and their families. Through our research findings, we aim to influence policy, improve services and support, and empower and inform service users, families and professionals.

In addition to the *Journey to Independence* project on which the present article is based, there are many other projects, both recent and current, that might be of interest to readers of PMLD-Link. These include

Food for Thought: Effective support services for disabled children who are tube fed. Contact Ruth Townsley

Committed to Caring - An investigation into the recruitment and support of shared carers for disabled children. Contact Beth Prewitt

Bridging the Divide: the experiences of people with learning difficulties and their families in making the transition between adults' and children's services. Contact Pauline Heslop.

CAN ADULTS WHO DO NOT USE WORDS HAVE CONTROL OVER THEIR OWN LIVES?

Natasha Snelham, a member of Swindon People First research team, recently posed the above question at an international research conference (IASSID's Inaugural European Conference in Dublin, June 2002). She answered it herself, with a resounding 'yes'. Natasha was one of three people with learning difficulties who were employed as researchers at Swindon People First, and who worked with Val Williams and Ken Simons from the Norah Fry Research Centre. As people who share the label of learning difficulty, Natasha and her colleagues consider that the right to self-determination can and must extend to all people who are so labelled. This includes those who do not use words, who have multiple or complex needs, or additional physical impairments. For the purposes of this article, I will refer to all of these people as those with 'high support needs', as it is a term that many self-advocates are starting to use.

Including people with learning difficulties within research

The research project that Natasha worked on was called *Journey to Independence* and it was funded by the Community Fund. At Norah Fry, researchers have long been concerned to make their research relevant to the concerns and issues of people with learning difficulties themselves. For instance, research projects are generally guided by advisory groups that include consultants with learning difficulties (see Ward and Simons, 1998), and the results of research are made accessible to those whom they concern, in particular through the *Plain Facts* project (Townsley 1999). The move to include people with learning difficulties as researchers is part of this development, and recognises that disabled people generally have a right to determine, not only their individual life paths, but also the construction of knowledge about their own lives and options (See Gramlich et al. 2000; Williams 1999; and Walmsley, 2001 for overviews of participatory methodology). However, can this movement towards self-determination include those with high support needs, or are they once again left out in the cold? This article aims to consider some of these issues, drawing in the main on data from the *Journey to Independence* project.

Direct payments autonomy

Journey to Independence set out to examine direct payments (Department of Health 1996), which is an option whereby disabled people can receive money to organise their own supports, rather than relying on services provided by local authorities (Hasler et al. 1999). This system turns the tables on the usual social order. Instead of disabled people being under the control of

others, they can now be employers, responsible for the personal assistants they employ. Taking on such responsibilities naturally poses some challenges, and direct payments support schemes exist in most areas to ease the process. Generally, direct payments support schemes are run by disabled people's organisations, such as centres for independent living, and they will help people to find a personal assistant of their choice, and to manage the technical aspects of being an employer.

Independent living in general, and direct payments in particular, are all about individuals having more control and autonomy in their lives, and these are very relevant goals for people with learning difficulties. In fact they are made explicit in the Government's learning disability strategy *Valuing People* (Department of Health 2001): "Direct payments are highly effective in enabling people with learning disabilities to gain greater control over their lives" (DoH 2001 p.48) and moreover, there is a recognition that *all* people with learning difficulties, including those with the highest support needs, "are capable of making choices and expressing their views and preferences." (DoH 2001 p.44)

However, progress of people with learning difficulties into direct payments has been extremely slow (in the autumn of 2000, the Department of Health was aware of only 216 people with learning difficulties on direct payments across the whole country, representing some 6% of the total number of direct payment users who were, in the main, people with physical or sensory impairments). The risk for people with learning difficulties is that they are perceived by others to lack the competence to make decisions, and that indeed the concept of 'learning difficulty' is almost defined by blanket assumptions of incompetence (Simpson 1999). Indeed the initial Guidance to Direct Payments stated that social services departments could only offer a direct payment to someone who was 'willing and able' to manage it. This effectively gave many local authorities a way to exclude whole groups of people from receipt of a direct payment (Ryan and Holman 1990). It was at this point that our research project started.

Methods

There were two strands in the main part of our research, one local to Swindon, and the other involving visits to ten different social services areas in the UK. On all these visits, self-advocate researchers were actively involved, in planning, writing questions for interviews, doing the interviewing and analysing the results. It was extremely important that they were in the driving seat, since the aim of the research was fundamentally to examine and discover what it takes to make direct payments work well for people with learning difficulties. They were the experts.

On all our visits, our primary aim was to meet people with learning difficulties who were direct payment users, but it was soon evident that these people were rare and elusive research subjects! Many areas in the country still have no more than a handful of people with learning difficulties who are using direct payments. However, we were also interested to meet a variety of other stakeholders, and the table below shows the people we interviewed, both locally and on our visits:

Table 1: Interviews carried out (on research visits and within the local area)

<i>People with learning difficulties who had a direct payment</i>	23
<i>Co-ordinators of direct payment schemes</i>	15
<i>Social workers (care managers)</i>	13
<i>Commissioners (social services senior managers)</i>	9
<i>Parents or other family members</i>	15
<i>Self advocacy groups, including people who did not (yet) get a direct payment</i>	7
<i>People supporting self advocacy</i>	10
<i>Service managers of staff</i>	11
<i>Personal assistants</i>	7
<i>Microboard member</i>	1
TOTAL	111

Early on in our research, it became evident that the team would be encountering people with high support needs, people whom they had perhaps not met in their everyday lives before. Just like any of us, they had to learn some of the skills for communicating with people who used methods with which they were unfamiliar. They learnt how important it was to ask beforehand how a person communicates, to spend time with someone, to use pictures and other visual methods, and to watch and observe how someone reacted through facial expressions, gestures or noises. They all found this task very rewarding, and some very meaningful encounters took place between self-advocates and people with very little communication.

One man, for instance, was able to choose between pictures, to show where he would prefer to spend his time - at home with his family, going out, or in the day service. He also enjoyed communicating by imitating movements, and so he and the self-advocate researcher spent some time making a relationship by sounds, singing and banging.¹

Of the 23 people we actually met who were direct payment users, six were people who communicated without conventional language use, who had additional physical impairments, or challenged others with their behaviour. In addition, we interviewed parents or family members of another three such people, whom we were unable to meet. These nine people constituted some 40% of the people on direct payments we met. If people have to be 'willing and able' to consent to a direct payment and to manage it, how is it that this system is including such a high proportion of people with high support needs?

Supported decision making

The option for direct payments has sharply highlighted some of the confusions over capacity for decision-making (Holman and Collins 2000). Should people with high support needs have others make decisions on their behalf ('substitute decision making') or should they be supported to make their own decisions ('supported decision making')? (Holman and Bewley 2001; Beamer and Brookes 2001). Instead of assessing the individual's capacity to consent, a supported decision making system would ensure that there are people around that person to support them in meaningful ways. The spotlight is turned on the capacity of the social network that a person has access to, and not on his or her own capabilities. The latest consultative documents from the Lord Chancellor's office (2002) in fact, appear to recognise and endorse this position:

'Everyone should be encouraged and enabled to make their own decisions, or to participate as fully as possible in decision-making, by being given the help and support they need to make and express their own choices.'

The current interest and encouragement for 'person centred planning' (Sanderson et al 1998) is closely tied to the concept of supported decision making for those with high support needs.

Making decisions about direct payments

How, then, did the nine people with high support needs whom we met manage to access direct payments, and to become employers of their own personal assistants? What did it mean for them?

One young man we met had only a few words, and tended to repeat what others had said. He was very active, but seemingly in a world of his own for much of the time. He was not able to express his choices verbally, but he could show who he liked and did not like: when he heard the car of someone he liked, he rushed to the window, and jumped up and down.

Each of these nine people we met was different, in their personality, preferences and support needs. However, what they had in common was a social network that could facilitate their choices. In most cases, this network simply consisted of their close family members, who knew them well and could understand what their facial expressions and sounds meant. For instance, sticking his tongue out was known to be a significant communication for one person. Having long familiarity with someone's communication style is essential. New people, such as care managers or direct payments support workers, have to build on the connections and knowledge of those who surround the person.

¹ All examples given in the text are anonymised, and based on more than one person we met.

Circles, trusts and microboards

For some of the people we met, structures had been built up, so that the individual's preferences could be formed at the centre of a network of close friends and family. There were various degrees of formality to these structures. First at the most informal, several people had circles of friends. A circle (Wertheimer 1995) is simply a group of people who come together to support a person. These circles are, naturally, very different, depending on the aims of the individual, the resources within the circle, and the circumstances.

When the option of direct payments is raised, an informal network can be a very useful structure, since by forming itself into an Independent Living Trust, it can be the formal recipient of money, on behalf of the focus person (Holman and Bewley 2000). A North American variant on this model is the microboard, which is virtually a small trust board, able to set up an individualised service around one person. All these structures, however, simply consist of friends and family, and at the centre of all of them is the person whose life choices are being supported.

Being the boss of your life

Our self-advocate researchers were keen to meet these people who, like them, sought greater control and ordinary life choices, but who needed support structures to enable them to express those choices. Were they really 'the boss of their lives', or did their support networks exert power over them? What struck the research team was the range of ways in which an individual could show what he or she felt and, in particular, say 'no' to something. It was that ability which really seemed to define 'being the boss'.

A woman in her forties had lived all her life with her parents. She needed total support to eat, to move around, and to keep herself from harm. However she always sat in on interviews for her support assistants, and she showed when she did not like someone by looking away, refusing to make eye contact, and by her facial expression. Her family or friends helped her with interviews, and always went by her choices when appointing staff.

Having a support circle, or a microboard, does not guarantee that the person is in control, but simply makes it possible. In the end the research team relied on their own observations and encounters with these nine people, and the evidence of the positive outcomes that direct payments had brought them, as summarised in the table below.

Table 2: Outcomes of direct payments for people with high support needs

Some people had more than one outcome.

<i>Ownership of a house (or shared ownership)</i>	2
<i>Voluntary work</i>	2
<i>Doing part-time job (paid)</i>	1
<i>Social trips to pub, or to neighbouring town</i>	2
<i>Joined clubs and sporting activities</i>	3
<i>Friendships gained through personal assistant</i>	4
<i>No change in circumstances</i>	2

For two people, direct payments had either failed or not made a great deal of difference to the pattern of their lives. Thus direct payments is not a panacea: being in control of one's life is always possible but it may require some careful listening, an attitude of respect, and much energy and creativity on the part of those who support an individual. As team members put it in their report:

'Having control of your life is about other people treating you with respect [...]. Everybody can make choices, but who has control over their whole life? Like everyone, we all need other people.'

What this research has demonstrated is not only the capacity of social networks to support decision making, but also the ability of self-advocates to relate to and represent those who do

not use words to communicate. They would very much like to include people with higher support needs in the self advocacy movement, pointing to the need for further action research in this area. Both self-advocacy research and supported decision making are concepts that challenge blanket assumptions of incompetence. As the Guidance to Direct Payments (DoH 2000) now states, people can be 'willing and able, with support'.

Our report *Journey to Independence* is to be published by BILD in the autumn of 2002, along with our accessible information pack for people with learning difficulties.

Val Williams and Ken Simons with Swindon People First Research Team

Norah Fry Research Centre
University of Bristol
3 Priory Road
Bristol BS8 1TX

REFERENCES

- Beamers, S. and Brookes, M. (2001) *Making Decisions: best practice and new ideas for supporting people with high support needs to make decisions*. London: Values into Action
- Department of Health (1996) *Community Care (Direct Payments) Act 1996*. London: The Stationery Office.
- Department of Health (2000) *Community Care (Direct Payments) Act 1996: policy and practice guidance*. London: Department of Health
- Department of Health (2001) *Valuing People: a new strategy for learning disability for the 21st century*. London: Department of Health
- Gramlich, S., Snelham, N. and McBride, G. (2000) Our Journey into the Unknown. *Community Living* Oct/Nov 2000: 9-10.
- Hasler, F., Campell, J. and Zarb, G. (1999) *Direct routes to independence: a guide to local authority implementation of direct payments*. London: Policy Studies Institute
- Holman, A. and Bewley, C. (2000) *Trusting independence: a practical guide to independent living trusts*. London: Values Into Action
- Holman, A. and Collins, J. (2000) *Funding freedom 2000: people with learning difficulties using direct payments*. London: Values Into Action
- Lord Chancellor's Department (2002) *Making decisions: helping people with learning difficulty deciding for themselves*. London: Lord Chancellor's Department
- Ryan, T. and Holman, A. (1998) *Able and willing? Supporting people with learning difficulties to use direct payments*. London: Values Into Action.
- Sanderson, H., Kennedy, J., Ritchie, P. and Goodwin, G. (1998) *People, plans and possibilities: exploring person centred planning*. Edinburgh: Scottish Human Services (SHS)
- Simpson, M. (1999) Bodies, brains and behaviour: the return of the three stooges in learning disability. In M. Corker and S. French (eds) *Disability Discourse*. Buckingham: Open University Press
- Townsley, R. (1999) Putting it plainly: producing easy-to-understand information for people with learning difficulties. *Frontline* 40: 12-13
- Walmsley, J. (2001) Normalisation, emancipatory research and inclusive research in Learning Disability. *Disability & Society* 16(2): 187-205
- Ward, L. and Simons, K. (1998) Practising partnership: involving people with learning difficulties in research. *British Journal of Learning Disabilities* 26: 128-131
- Wertheimer, A. (1995) *Circles of support: building inclusive communities*. Bristol: Circles Network UK
- Williams, V. (1999) Researching together. *British Journal of Learning Disabilities* 27: 48-51

NO ORDINARY LIFE

Paper given at a Seminar jointly organised by MENCAP and PMLD-Link

"We live in a society that sees people like my daughter as worthless. Why then, would it be one that delivers high quality services".

A quotation from a parent interviewed for Mencap's report *No Ordinary Lives* published last year . A rather sad comment on the society we live in in 2002.

Today I was kindly invited to come and talk to you as a parent although I am also a teacher working for Derbyshire LEA as a specialist support teacher for pre school children with special educational needs.

I want to share some of my insights and comment on the findings of the report as I find them too. However I do not wish to use this time just to bash professionals (I'm very aware that I am probably preaching to the converted) but I would like to look at how relationships between parents and carers and professionals can be improved and also, where there is evidence of good practice, to ask what makes it so?

Our family

Our daughter Victoria will be 19 this summer. She has profound and multiple leaning disability and cerebral palsy. She was very poorly when she was born but we received no diagnosis until she was 18 months old due to a deletion on the long arm of chromosome 22 and septicaemia in the immediate neonatal period.

We have three younger daughters, Suzannah, nearly 15, Eleanor 13 and Grace who is 8.

We made a difficult decision a long time ago that we would seek to find a home for Victoria to move on to when she left school. One of the most compelling reasons for this was the lack of quality support day services and opportunities available for young people with the degree of Victoria's difficulties when they leave school and 'fall off the edge'. I would probably have to put my career further on hold in order to be there for Victoria. Perhaps it's anno domini but I just don't have the energy which I used to have and I have three other children to nurture.

I used to believe that as the children grew up life might become easier. It does in some ways but good parenting involved expending an enormous amount of time and energy and sharpens up your listening skills! All the girls are real chatterboxes. The local day centre in Ashbourne near where we now live has recently been refurbished. It is over subscribed, and has clients whose ages range from 18 to late 50s. Victoria spent a few sessions there in the summer holidays but needed one to one support to gain access to meaningful learning experiences.

I have a job share position and thoroughly enjoy my work which I find very rewarding .

Being a parent and a professional brings its difficulties

People are judgmental

Why complain - you're an expert! -

- must have all the answers!

It still hurts, I'm no different.

I do have the skills and ability to challenge and complain and often do, but at great personal cost. Health has been affected - two major operations in the last 4 years and ongoing treatment for clinical depression.

The transition from children's services was a night mare. It was perhaps more difficult because we moved back to this area from Birmingham and until I went into hospital as an emergency in October 2001 we hadn't been able to access any respite care.

Criteria for respite in some places is ludicrous - don't take people who are not mobile. The other option had no downstairs facilities for sleeping or changing and no lift. The staff were unhelpful and unwelcoming and Victoria didn't fit into the provision they were able to offer.

When I discovered I was going into hospital with three days notice, Victoria received emergency care at a small hostel in Ashbourne linked to the day centre, but during my recovery a risk assessment was carried out by the physio - no I wasn't informed - until we were told that Victoria would not be offered any future respite there because there was only one downstairs room which was already spoken for by three other clients who were in wheelchairs and she could not walk upstairs every time she needed to use the loo or be changed. No equal opportunities there.

The report mentions families commenting about the quality of care given in respite care

Problems included:

- Dehydration
- Pressure sores
- Not being changed or washed thoroughly after soiling.
- Too many different care givers

I would add to the list in the report:

- Medication forgotten
- Lack of communication
- Reluctance to follow through on specific programmes to ensure continuity every day
- Giving night time medication without our permission.

So in many respects we were pushed into a corner to look for something sooner rather than later with Victoria's due date for leaving school approaching. I was made to feel guilty about working and having other children.

The report discusses in depth the impact on family life

We have been a very isolated nuclear family. Our immediate relatives have been unsupportive. Peter's mother adored Victoria but was very crippled with arthritis and died a few years ago. Not one of our respective siblings ever took Victoria out.

I always needed an extra pair of hands, it comes in handy when you have three children in nappies as we did for a while, but I have generally found it easier to get on without help because it was easier on my nerves if not on my body!! Unreliable help is no help at all.

Doing things that ordinary families do was difficult, for example, going to a farm or a zoo. The girls hated Victoria to be upset or to cry, which she often did, so they would not want to go again. Including Victoria became harder in many ways as she grew older. The girls found it hard to talk about Victoria at school but would come home upset when peers said they didn't believe they had a sister with special needs. They were fearful of bringing friends home and worried about Victoria shouting out during concerts etc at school - not cool, or weed through her pad and made a huge puddle on the floor. It has not been easy.

I quote from the survey:

"After a full day of care, the effort to make a social gathering seems like climbing mount Everest".

It was like climbing mount Everest sometimes to read Grace a bedtime story or test the girls spellings, listen to their music practice and look after Victoria. She is quite swift at pottering around in the kitchen and needs watching twenty-four hours a day.

Going shopping is hard work for us all. I've thought about using the internet but I prefer the hands on sensory experiences of shopping and its one thing Victoria really enjoys doing. Tesco now has different types of trolleys and yes there is one for a child with disabilities (and offer help to get around) - Oh if only it had been so a few years back when Victoria's involuntary arm movement knocked the largest bottle of whisky you could get!

People do give us funny looks sometimes. I don't mind the staring now. Children are fascinated by Victoria and like to have a good look. Sadly their parents pull them away. I think it's sad that they reinforce social prejudice by pulling children away and behaving as if she's from another planet.

What people say!

It is often the well meaning comments which hurt the most. Someone at our church commented recently that they hadn't seem my elder girl recently and wanted to know what had happened. I was very touched by her concern and told her all about Victoria's new home. Then she added "well it must have been just like taking a dog to the kennels, strange at first but they get used to it". I said nothing and walked away.

Our Christian faith has been a great source of strength over the years. But our experience of Church has been a mixture of conflict and comfort. The church has been slow to respond to inclusion and is not always accepting.

However it has been within the church that Victoria has had a most profound influence and has been able to develop some real friendships with others. She loves to go to Church, has to sit very near the front adores a good band especially if her dad and sisters are playing. She likes to sit in the same row each week. In our previous church in Birmingham, Victoria befriended a married couple in the late fifties, they both had mild learning difficulties. Victoria adored them. She would always wants to go and greet them. We have had similar experiences in our church at Doveridge.

Coordination of services

This can be dire - one family had 25 different people involved. I have attended case conferences where I haven't known half the people and not had a clue they were going to be there or what their role was.

You can spend all the free time you have chasing things up, its how I spent my days off during my job share before Victoria moved into her hew home. I visited Victoria last week and took her out for a pub lunch with her key worker. She commented to me that she didn't know how I'd managed to cope. She had been chasing up several appointments that morning and was feeling very frustrated.

As a professional I am embarrassed and horrified by some of the stories I hear and witness, derogatory comments made about parents and to parents.

Working in partnership with parents

This could be a catch phrase of the Millennium but I fear it is in danger of losing its real meaning if indeed it ever found it. I have been humiliated as a parent many times.

- I've been told to shut up during consultations.
- I've met lots of doctors - many have their own prejudices and opinions which they don't keep to themselves.
- Exclusion during planning for transition, for example Health Authority Nursing Care Assessment with refusal to share criteria being used to make a judgement; failure to include parents in information gathering; finding out the result by accident! The

criteria were set against strict medical guidelines so that Health would only ever have to contribute to the cost of the care in the very smallest number of circumstances possible.

Enough doom and gloom.

I had the most wonderful encounter a couple of weeks ago with Victoria's new rehab consultant in Chesterfield. He sat and watched and listened, we discussed openly and frankly what his level of support should be and how that could be arranged. He actually told me face to face that Victoria was a huge credit to me.

He was very impressed with how well she behaved and could see how we had worked hard as a family over the years to develop Victoria's best potential. As a very experienced doctor specialising in PMLD he told me that the 18 years Victoria had spent with us as a family were the greatest gift we could have given her, and now it was their responsibility in partnership with me to ensure that she is able to maintain the skills she has. I left that room feeling great. A rare experience.

The majority of families interviewed for the Mencap report said "Social services don't tell you what you're entitled to"

True. There is lack of information about what help is available and entitlement to it. We know that resources are finite, but its too easy to say that to a desperate parent. I don't expect a social worker to start going on about resources before she has even listened and had time to carry out a fair assessment of need.

The Children Act 1989 and Community Care Act 1990 place the responsibility for providing information about their services onto the local authority. Glossy brochures are nice to give to people but the content has to mean something.

Our social worker had an accident and was off work from April until August last year. It was a very difficult time when we were in the midst of trying to sort out a placement. To compound the difficulties Derbyshire suddenly underwent a huge restructuring of its services for people with learning disabilities so there was a complete change of people at management level in this area. In July when things were going from bad to worse I made such a fuss that we were given an temporary social worker to come in and sort things out until our social worker came back from her sick leave. This lady did more in two visits than anyone else had during the last 12 months.

Why was that?

- She was 100% professional;
- She knew her job;
- She was able to listen;
- She was able to assess Victoria's needs and the whole family;
- She didn't have the information at her finger tips she went away to find out and contacted us by return;
- She was committed to doing her job properly.

Because she was on the ball so to speak, she found out that a client had passed away at a specialist care home in Chesterfield in May and they were looking for a new client to fill the vacancy.

She arranged for us to visit and things moved forward from then, not with the best communication; had I not badgered the social services everyday I don't think anything would have happened; we were never actually informed when the funding had been agreed. A friend of ours, also a county councillor, rang us to say how pleased he was and was amazed that we had not been informed officially. The previous social worker came back but Victoria finally moved into her Home in late November with funding of £40,000 a year secured for fees to include 24 hour care and a support worker for three days a week to access activities in the community.

Transition to adult services

Transition from child services to adult services appear to be in complete turmoil. There have been improvements overall in paediatric services since Victoria was a baby, although there are still plenty of examples of bad practice to be found I'm afraid to say. The truth is that if you don't ask the right questions you don't get the right answers. How are parents expected to know what to ask or how to approach some of the 'gods' in the medical profession?

There have been significant changes in education legislation, moves towards inclusion, and the rights of children to broad and balanced and differentiated curriculum to meet their educational needs in school.

But planning for transition from school is a shameful tale of woes. Many schools can't get social services to start attending annual reviews until the young person is in their final year at school. What chance does that give parents to consider any options.? Social services won't tell you about the options often because they may not even know what is available - for example, that residential college may be an avenue to explore - but of course, people with PMLD are excluded from that because the funding for residential colleges is capped in such a way that they are unable to provide the level of support which such students needs to access learning.

Proposals

- A Code of Practice
- Openness and more liaison between health and social services
- Learning disability partnership boards
- Include carers in the design and delivery of better services
- Direct payments and a complete overhaul of how fees are agreed with providers. At present it seems that a care home can pluck any figure and expect the local authority to pay. If a home does not really want your child they will demand a higher figure knowing the funding will not be available.
- Person centred approach
- More information
- Key worker
- Be realistic about the cost of caring for children and adults with PMLD at home.

All staff need far more training: opportunities to develop skills to improve interactive approaches and communication skills with clients with PMLD. They need competent qualified people with high skill levels, which requires training modules that promote better understanding of needs of people with PMLD.

The adult sector has to move even further away from the old attitudes of CARE and start to see people as individuals with rights to access life long learning programmes which are suitable to their needs, and to provide ongoing opportunities to maintain existing skills to promote each individual client's best potential.

Julia Dixon

Parent

Opportunities for Physical Activities for Adults with Profound and Multiple Disabilities - a new scheme

My profoundly disabled daughter Nanette and I have embarked on a project that we hope will fill a gap for severely disabled young adults.

Our vision is to provide physical opportunities for people with profound and multiple disabilities. We are thinking in terms of the kind of soft play facilities that children enjoy, along with other activities like trampoline bouncing, swings, rocking equipment and so on.

While we have no wish to exclude anybody from the project, we feel that children already have a certain amount of provision and that there is also some sports provision for others, for example spinally injured people. In our experience, there is very little provision for the most severely disabled and dependent adults. As Nanette was growing up, there were a few activity options for her; but at the age of 21, as an adult, she seems to fall through the net and I am sure there are plenty more people like her.

I have developed a timetable in which I take her horse riding in Cheltenham, (a round trip of 30 miles), to hydrotherapy in Swindon (a 60-mile round trip), music therapy in Cricklade, Wiltshire, (about 40 miles a trip) and as much massage and therapies as I can manage. But all this travel is pretty exhausting and, as a single parent who has been on benefits since my daughter was adopted at the age of ten months, the cost is a big burden too.

I have succeeded, despite considerable opposition, in securing financial support from the Independent Living Fund which allows us to purchase four nights of sleep a week for me plus some daytime care in the home. It is the support and encouragement of our new carers that has stimulated us into looking at this challenging new initiative.

During the last 18 months I have produced and distributed 500 leaflets on our home PC. The responses suggest that we have correctly identified a need and that we can expect considerable endorsement. We have gathered a small group of people who are committed to the project and are promised support from Mencap. We believe we have located suitable premises but are at a very early stage with this exciting project. I am repeatedly told that there is demand for such an activity group and we hope we are creating just the sort of project that severely disabled adults desperately need.

We would welcome contact with anyone who might be interested - potential clients, their families and carers as well as suggestions, ideas and information.

Connie Williams
c/o Minchinhampton Parish Council
Minchinhampton Library
School Road
Minchinhampton
Gloucestershire, GL6 9BP
www.good-moves.org.uk
E-mail: admin@good-moves.org.uk
Telephone/Fax: 01453 - 886465

Local Rate: 0845 - 5489892

'COMMUNITY CONTACTS' FOR PEOPLE WITH PROFOUND AND MULTIPLE LEARNING DIFFICULTIES: SOME GHANAIAN PERSPECTIVES

Introduction

In Ghana residential institutions are the main providers of care, schooling and training for children and adults with profound and multiple learning difficulties (PMLD) and, consequently, there are few opportunities for community involvement. As in the UK, most people with learning difficulties in Ghana spend the majority of their lives in an enclosed world, populated either by other people with learning difficulties or by paid support staff (Simons, 1997).

In Ghana, however, residential living exacerbates the situation and the lack of community contact for many people with PMLD has been coloured by eugenic, medical and psychological considerations. In the past children with the most profound needs were left to die; more recently, however, a social model of disability has emerged but community contacts are often thwarted by the impediments that society places in the path of those individuals with complex needs.

Human rights

Paradoxically, the history of the inclusion of people with PMLD in Ghana, as in many other countries, indicates that they originally lived within the community, even though they were generally discriminated against and often ostracised. It was, however, the introduction of care homes and schools that established institutionalised, exclusionary practices as a way of life for many such individuals and isolation from the community became a pattern of life. Isolation became so entrenched over the years that the establishment of community contacts required considerable levels of initiative and effort from the staff who were responsible for the education and care of those with complex needs. Although the changing of the attitudes of the general public are important, it is also necessary to change the attitudes and approaches of the staff concerned.

The role of the schools and their staff

There is a historical basis for the contemporary trend of isolating those with profound and multiple learning difficulties in Ghana, which was probably developed to create a haven for children with learning disabilities. Davison (1993) argues that the location of establishments may be considered a reflection of society's attitude towards such children and states that:

"If the children in the establishment are deemed capable of involvement in the community, then the establishment may be located openly in the community."

(pp.146-

147)

This is clearly not the case in Ghana, where at present society decides who *should* benefit from community contact and who *should not*. Boarding schools are regarded as elitist establishments for the able and their presence appears to indicate approval of exclusionary practices.

In the case of many people with profound and multiple learning difficulties such exclusion has denied them the opportunities for community contacts and access to facilities. It should, however, be stressed that where facilities are sited within a community, automatic contact between the pupils and members of the community is not necessarily guaranteed, and the encouragement of teachers, residential staff and carers to make a commitment to community involvement is critical. The research of Lowe and de Paiva (1991) (cited in White and Dodder 2000) confirmed that opportunities to participate in community activities depend on the commitment of community placement staff.

Community perceptions and apprehensions

At the First Joint National Conference of Special Education in Ghana (November 1998) it was clearly stated that society's attitude to disability continues to be negative, even at the end of the twentieth century (Communique No. 7 1998).

While it would appear that the attitudes of some sections of society have changed in the last three years, there is still some apprehension about children with learning difficulties in general and those with profound and multiple learning difficulties in particular. It is important not to categorise all members of Ghanaian society as unwilling to make contact with those with complex needs. Nevertheless, some husbands have gone to the extent of divorcing their wives for having children with profound and multiple learning difficulties (Quansah 1998).

This, and similar evidence, points to a complete lack of awareness of the contribution that children and young people with such needs can make to the community at large. 'Community education' is imperative, but must be developed from a realistic base. Churches still play an important role in the lives of many people in Ghana and it is therefore vital to harness their potential in approaches to the changing of attitudes.

Community education

As has been discussed, the apparent lack of any 'social education' among many communities in Ghana ensures that people with profound and multiple learning difficulties are regarded as a cursed group and are excluded from full participation in community activities. Consequently as the churches retain a strong influence on Ghanaian society they have the potential to provide a firm platform for 'community education' in various ways and on many aspects of disability.

One obvious approach would be to challenge a community's perceptions by encouraging its members to meet people with disabilities, including those with PMLD. McConkey and McCormack (1983) suggest that such a development would help to make its members realise that their negative impressions are mistaken and, hopefully, would bring about changes in their attitudes. They further argue that community education must begin by finding out what the *general public* knows and thinks. Videos, seminars, leaflets and films can provide invaluable information on the nature of disability and should encourage the dissemination of positive images.

In the main, residential schools have contacts with their local churches and they should be encouraged to *open their doors* to the general public and to provide opportunities for school staffs to allow children with PMLD to participate in community activities. This is not to suggest that community education should become part of a religious crusade, but that churches could provide a model of respect, dignity and human rights.

The challenge to strengthen the staffs' commitment to community placements needs to be addressed through their professional development. In the UK opportunities for staff training and the education of professionals involved with children and young people with PMLD are far greater than in Ghana. Nevertheless, the introduction of special education as a general course of study in some of the universities in Ghana has helped to sensitise many teachers to the needs of people with disabilities.

It is hoped that as more people in Ghanaian society become aware of learning difficulties in general, people with profound and multiple learning difficulties will become more widely accepted by society at large.

Mawutor Avoke
School of Education
The University of Birmingham
Edgbaston
Birmingham B15 2TT

e-mail: Avokemawu@yahoo.com

References

- Joint National Conference, Ghana (1998) 'Communique', in *Pre-plan for Special Education Services in Ghana in the 21st Century*. (Winneba: 23-24 November)
- Davison, A. (1993) 'The impact of the psychological environment in residential group care and educational settings', in E.W.Anderson and A.J. Davison (eds) *Applying the Children Act 1989 in Boarding and Residential Environments*. London: David Fulton Publishers
- McConkey, R. (1998) 'Community Integration and Ordinary Lifestyles' in P. Lacey and C. Ouvry *People with Profound and Multiple Learning Disabilities: a collaborative approach to meeting complex needs*. London: David Fulton Publishers
- McConkey, R. and McCormack, B. (1983) *Breaking Barriers: Educating People about Disability*. London: Souvenir Press
- Quansah, A. K. (1998) 'Problems facing the disabled ' in *Pre-plan for Special Education Services in Ghana in the 21st Century*. (Winneba: 23-24 November)
- Simons, K. (1997) 'Residential care, or housing and support?' *British Journal of Learning Disabilities* 25(1) 2-6
- White, D. A. and Dodder, A. (2000) 'The relationship of adaptive and maladaptive behaviour to social outcomes for individuals with developmental disabilities'. *Disability and Society* 15(6) 897-908

Facilitating Affective Engagement with Children with Autism through the Medium of Colour

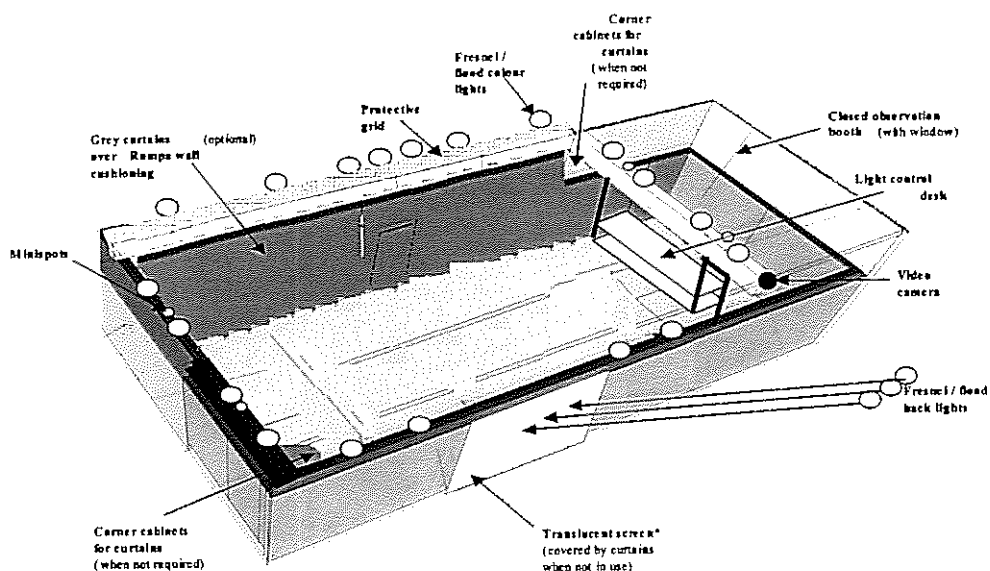
Introduction

This project being carried out at Sunfield School, Clent is researching the use of colour as a backdrop for social interaction with children with severe autism. In many ways the principles are closer to those of music therapy, but changing colour is used to create the mood instead of music. The methodology is constantly evaluated and revised as the project is developed through action research.

It is generally recognised that colour affects us at the rather deep and only partly conscious level of emotion and mood. This is reflected in our culture and language in expressions such as 'see red' and 'feel blue' etc. The intention is to reach and interact with the child at this non-intellectual and affective level.

Sessions take place on an individual basis in a specially designed room in which the whole interior colour can be gradually altered through dimmer-controlled lights.

Plan of the Colour/Light Room



This project was introduced in PMLD-Link Vol. 12.2 (1999) and has now been running for approximately three years.

Why is it important to interact at the emotional or affective level?

There is a considerable body of opinion which suggests that an underlying emotional disturbance may be one of the reasons why children with autism cannot easily participate in normal interpersonal relationships (e.g. Frith, 1989, Jordan and Powell 1995, Williams 1992, Gerland 1997). It is also generally accepted that learning is contingent upon good interpersonal relationships (Collis and Lacey 1996) and therefore, despite the difficulties, it is felt worthwhile to concentrate on developing interactive skills as a precursor to learning (Sherratt and Peter 2002).

Looking more closely at the question of the role of emotion in relationships, Hobson (2002) sees the main root of autism as a lack of emotional connectedness with other people. In fact he concludes that autism may be the result of a disorder which prevents the developing child from experiencing what he calls 'vital aspects of interpersonal relations'.

Furthermore he submits that the development of thinking itself is dependent on healthy interpersonal relationships. It therefore appears that an ability in the realm of 'affective cognition' is necessary if interaction with another person is to have meaning or significance and that this forms the essential framework on which learning can take place.

Colour, apart from its emotional connotations in our culture seems to have particular significance for people with autism. Brief mention will be made of three writers who have a diagnosis of autism. Wendy Lawson describes how she was particularly fascinated by colours and says that for her they evoked 'intense emotions and feelings of ecstasy' (Lawson 1998, p.4). Gunilla Gerland relates how her inner world was one of colour, everything had its own colour, words, people, feelings, atmospheres etc. Although she could not necessarily understand a feeling she could perceive its colour (Gerland 1997). Donna Williams also describes an inner world of colour, with different feelings being perceived as different colours (Williams 1992). Furthermore different colours of light affected how she felt; for example blue had a mesmerising effect while red made her alert and active (Williams 1996).

In this research an attempt is made to facilitate the sharing of meaningful experiences by enabling the emotional or affective aspect to be shared as well as the cognitive. Therefore to help create this possibility during an interactive sequence, the appropriate colour changes are used to augment and enhance the varying moods. Expressive movements or gestures are accompanied by sweeping changes of colour.

The 3 Stages

1. *Observation in the Main Colours*

Firstly the child's behaviour is observed in the main colours of blue, red and green in order to establish how the child is affected by the different colours. This information is used in the later stages.

2. *Dialogue between Child and Colours*

The lights are then sensitively altered in response to the child's behaviours so that there is a sort of reciprocal 'dialogue' between gesture and vocalisations of the child and changing of the lights.

3. *Intensive Interaction*

An adult then gradually begins to join in with the child's gestures and behaviours to create a spontaneous and creative 'dance' or game still backed up by changing colours. There is a particular emphasis on sharing the mood and emotional content of the movements. It is the changing colours which augment this mood. As this develops there is continually more input from the adult, leading on to turn taking, imaginative play and communication through language.

Case Studies

Alan

Alan was 9 years old, was non-verbal and had a diagnosis of severe autism. He seemed happy to come into the colour room and smiled and laughed as the colours changed.

Stage 1

His response to the different colours soon became clear. It appeared he found red arousing and sometimes almost overpowering, often becoming agitated and sometimes frantically flicking a toy or hiding his head in the curtains. In blue he was calmer and in green he became much more relaxed. Yellow made him bright and cheerful.

Stage 2

When Alan began to move his head from side to side the yellows would fade up and down in time with his movements. Yellow was chosen because it seemed to make him active and happy. He soon realised that he could 'control' the lights by his movements and a 'dialogue' developed in which the yellows would respond rhythmically to his head and body movements.

Stage 3

Sitting some distance from Alan and behind him, the adult slowly began to mirror his head and body movements. To begin with, it was not at all clear whether Alan was taking any notice of the adult or not, but after a while he turned towards the adult, seemed interested in seeing his movements copied and then clearly started to interact by exaggerating his movements and making excited squeaking and shouting noises. All the time the yellow lights were responding in both timing and amplitude. At first, Alan always led the 'dance' which involved many different movements such as swaying from side to side, jumping up and down and running round and round. As the sessions progressed it became clear that for Alan the adult was now not only an essential part of the 'game' but also someone who could lead as well as mirror. He managed turn taking when, holding hands with the adult he took part in a 'You pull, I pull' game. In this case a mood of tension for the effort of pulling was created with red, the relaxation afterwards with blue. Alan has come a long way towards being able to take part in reciprocal interactions with another person.

Anna

Anna was 10 years old and had Downs Syndrome as well as being diagnosed as severely autistic. She had no meaningful speech though she would occasionally imitate words, she avoided eye contact, and play would always be on her own terms. She enjoyed rough and tumble but could be quite rough and aggressive.

Stage 1

Anna would sit cross-legged and made intermittent babbling sounds whilst rocking from side to side. In red, these would be animated and fast, whereas in blue and green she tended to be quieter and calmer. These differences were not always consistent but the trend was to be more aroused in red and less in blue and green.

Stage 2

In the 'dialogue' phase a sort of conversation was made up whereby the red lights would flash in response to her vocalizations. A sort of ebb and flow was created between agitated or cross sounds augmented with strong red, and gentle quiet sounds or silence in blue-green.

Stage 3

The interaction started by picking up on Anna's different demeanour in red and blue-green. Play would be energetic and forceful in red whereas it would be calm and gentle in blue-green. With the augmentation of the colours she was helped to gain a deeper experience of the different moods. Over the course of several months her playing style became much more responsive and her tendency to aggression diminished considerably. Eye contact improved dramatically, with much more smiling and laughing, and she became far more willing to imitate words. A delightful and charming personality was becoming ever more evident.

Summary of Findings

In very general terms we are able to make the following statements about the effects of the colours:

- The preliminary research suggests that colours do have an effect on mood and behaviour.
- In general, red tends to produce excitement while blue and green have a calming effect.
- Children enjoy alternating colours, but become uneasy if one strong saturated colour is prolonged.
- For a child where it has been established that blue and green are calming, it is sometimes possible to use these colours deliberately to pacify an excited child and allow them to relax.
- For a child with autism, it is possible to use changing colour as a medium for interaction. They will readily take part in reciprocal interaction and seem to enjoy it.

In addition to this we now feel in a position to make the following specific statements about mood and behaviour:

- There is a marked increase in vocalisations or attempted vocalisations during colour sessions.
- The children are often more attentive in the room than they are reported to be at other times. Many are able to concentrate for longer periods of time than they would otherwise.
- Negative behaviours are markedly decreased in the room even if they were occurring immediately before the session.
- Social foundations such as turn taking, waiting, spontaneity and demand tolerance are increased in the colour room environment.
- The colour sessions are enjoyable and the children are often seen to be happier in post session observations.

Diana Pauli and Melanie Smart

Sunfield School

Clent Grove

Clent

Stourbridge

Worcestershire DY9 9PB

e-mail: Melanie@Sunfield.worcs.sch.uk

References:

Collis, M. and Lacey, P. (1996) *Interactive Approaches to Teaching: A Framework for INSET*. London: David Fulton

Frith, U. (1989) *Autism - Explaining the Enigma*. Oxford: Blackwell

Gerland, G. (1997) *A Real Person*. London: Souvenir Press

Hobson, P. (2002) *The Cradle of Thought*. London: Macmillan

Jordan, R. and Powell, S. (1995) *Understanding and Teaching Children with Autism*. Chichester: John Wiley

Lawson, W. (1998) *Life Behind Glass*. Lismore, Australia: Southern Cross University Press

Pauli, D., Egerton, J. and Carpenter, B. (1999) The Sunfield Colour Impact Project. *PMLD-Link*, 12(2), 12-16

Sherratt, D. and Peter, M. (2002) *Developing Play and Drama in Children with Autistic Spectrum Disorders*. London: David Fulton

Williams, D. (1992) *Nobody Nowhere*. London: Corgi

Williams, D. (1996) *Like Colour to the Blind*. Toronto: Doubleday

report back

COMMUNICATION AND PMLD - ASSESSMENT AND BEYOND

This conference for speech and language therapists, teachers and others working with children with PMLD was held at Penhurst School, Chipping Norton on 29th May 2002.

The idea for the conference grew out of a desire for professionals working in the field of PMLD to have more opportunities for increasing their skills and for networking together. We suspected that few such opportunities existed, and were delighted when this hunch was confirmed by an enthusiastic uptake of places by delegates from as far afield as Manchester, Devon and Essex. Some even had to be turned away when we reached capacity numbers. Many were roped in to help, with Penhurst staff acting as hosts, and Oxfordshire Speech and Language Therapists chairing workshops. Many hands did indeed make light work, as much effort was required to turn school classrooms into an acceptable conference centre with the required audio-visual aids.

The morning sessions focussed on the topic of assessment. Once the 75 delegates were settled, Juliet Goldbart, lecturer at Manchester Metropolitan University and co-author of *Communication before Speech* set the scene brilliantly with a keynote speech on **A Developmental Framework for Assessment**. She covered paradigms for understanding learning disability, social, cognitive and communicative development in infancy, and levels of communicative functioning based on the Early Communication Assessment, with emphasis on intentionality and learned helplessness. Theory was helpfully amplified with many practical illustrations, making this a stimulating hour.

Delegates then had the hard task of choosing between three workshops on the assessment theme - *Assessing for Switches* by Jackie Ayre, OT at the ACE Centre; *The Redway Assessment* by Ann Miles, teacher at the Redway School; and *Using Video for Assessment* by Penny Lacey from the University of Birmingham who had kindly agreed to be drafted onto the team at short notice. All were very practical and generated much discussion (and occasionally polite disagreement!) amongst the eager participants.

An excellent lunch (thanks to Rosemary our Housekeeper and her merry band of helpers) fortified us for the afternoon session. There was also time to peruse the very interesting and relevant displays contributed by Liberator, Q.E.D. and Penhurst's umbrella organisation, NCH. A demonstration of Penhurst's newly equipped multisensory environment was also arranged by Penhurst staff.

For the afternoon session, Helen Cockerill, Specialist SLT from Guy's Hospital, arrived with her usual sense of humour only just intact due to breaking down 10 minutes into her journey and having to be towed home and start again! However, she delivered her keynote speech on *Developing Communication with Assistive Technology* with professionalism and energy, challenging our preconceived ideas and practices.

Again, there were three excellent workshops to choose from in the afternoon - *Joint Action Routines* by Juliet Goldbart; *Creating a Total Communication Environment* by Tony Jones from Liberator; and *Developing a PMLD Curriculum* by Gillian Hazell, SLT at the Ace Centre. It was again stimulating to discuss practical and relevant topics with fellow professionals in the same field.

Having been bombarded with information and ideas, the plenary session was used as an opportunity to break into small groups of 4 or 5 to begin to reflect on implementing some of what we had learnt in our own workplaces. This aimed to combat the familiar routine of returning to work, filing the conference notes, and losing their impact on our real working lives. Indeed, it is hoped that this conference will not only have been a 'good day out' which

it certainly was, but will have stimulated real development of thought and practice, to the benefit of the children with PMLD who are the focus of our working lives.

Following on from the success of this year's conference, there are plans to make it an annual event, so watch out for publicity early in the New Year!

Janet Trebilcock
Specialist Speech and Language Therapist, PMLD

OBJECTS OF REFERENCE: THEIR ROLE IN SUPPORTING LEARNERS WITH MULTIPLE DISABILITIES

As many readers will be aware, in recent years a specialised technique employing 'Objects of Reference' (OR) has evolved to help develop communication between children who have multiple disabilities and their parents and educators. In its simplest form the technique involves systematically utilising real objects from the child's environment to refer to a person, place or event in their lives. For example, presenting a cup to the child may come to signify 'it's drink time'. As the child's understanding develops, the OR can be adapted by reducing its size and changing its form, for example a small piece of towel attached to a card may be presented to the child to show that the next lesson is in the hydrotherapy pool. Several cards with different ORs on them may be used to represent a sequence of events in a child's day and form a simple timetable for the child.

The use of ORs is now well established throughout the United Kingdom among teachers of children who are deafblind, and research into curriculum access for deafblind children (Porter, Miller and Pease 1997) found that 54% of teachers working with this population used this technique. However, ORs are also being used extensively with children with a wide range of learning difficulties.

Despite an apparent increase in their use however, no data has been gathered which gives a reliable national picture of the "use and the evaluation of the use of object symbols" (Park, 1995). Further, McLarty (1997) notes that, the technique has often been applied in a piecemeal fashion, separate from any supporting context or theoretical framework and suggests that "there is comparatively little written material available for those who wish to develop this approach in their own practice with children who have severe or profound and multiple disabilities". In the absence of research evidence, the claims for the success of this technique with children in different populations still remain largely anecdotal.

Given the lack of documented practice in the area, the purpose of this conference was to offer a forum for dissemination of both national and European developments and to provide practitioners with a firmer understanding on which to continue to develop their own practice.

Following an introduction to the day by Mike McLinden and Jill Porter, Marleen Janssen provided an overview of the origins and developments of objects of reference. Marleen was an invited speaker from Saint-Michielgestel school in Holland and was personally involved in some of the early developments in the use of objects of reference as a method of developing the communication of children who are deafblind. Following Marleen's presentation Liz Hodges from the School of Education and Laura Pease from Whitefield Schools offered a UK perspective with a particular focus on issues relating to the use of objects in the classroom. Their presentation highlighted that objects of reference, when used as part of a communication continuum, can help learners to develop symbolic communication skills, whilst noting that other means of communication may be more appropriate for learners who are not ready to use objects or who no longer need to use concrete communication systems.

Following lunch, participants divided into seven discussion groups each of which explored a broad theme relating to the use of objects of reference with children who have learning difficulties (e.g. Objects of Reference and Children with ASD, Objects of Reference as a

route to literacy etc.). Each discussion group was asked to identify one 'priority theme' for the Panel discussion at the end of the day.

Following the discussion groups Adam Ockelford from the RNIB explored future developments of objects of reference in education. His paper considered three main issues: 'where are we now?'; 'where next - research'; and 'where next - ideas and people'. Adam highlighted the need to find out not only at what level objects are being used with children, but also their perceived effectiveness. He outlined a number of possible developments in their use including possible links with technology, as well as the use of objects of reference in mainstream educational settings. Following Adam's presentation, the Panel Discussion provided an opportunity to explore further the priority issues identified in the discussion groups.

Over 150 delegates from a range of educational settings attended the Conference and the evaluation to date suggests that the day provided people with some important practical issues of debate, particularly with respect to the nature of progression. Edited conference proceedings are planned and should be available in Autumn 2003. Further details will be published in the next edition of PMLD-Link. Meanwhile, if anybody wishes to discuss any aspect of the day further, or would like to be put on the mailing list for similar functions at the School of Education they are welcome to contact one of the conference organisers.

Mike McLinden, Liz Hodges, Jill Porter
School of Education
The University of Birmingham

WHAT MAKES THE DIFFERENCE? LINKING PARENTS AND PROFESSIONALS: MEETING THE NEEDS OF PEOPLE WITH PROFOUND AND MULTIPLE LEARNING DISABILITIES

This seminar was jointly organised by Mencap PMLD Section and PMLD-Link on the 14th May 2002. The seminar was intended to provide a forum to extend discussion of issues raised in the report *Valuing People: Voices Unheard* (Mencap 2002) on the quality of links between parents and professionals, and the quality of service received by people with Profound and Multiple Learning Disabilities.

Professor Barry Carpenter, OBE chaired the seminar and in his introduction he commented on the shared agenda and common goals of the two organisations, and applauded this joint endeavour.

Two parents elaborated upon the issues from the point of view of their own experience.

Julia Dixon, mother of Victoria who is 19, described the difficulties, and the final success in finding residential accommodation for Victoria. Her paper is produced in full in the article 'No Ordinary Life' in this issue.

Jan Roast, mother of Gemma gave a moving and thought provoking account of the memorable challenges they faced from the earliest years until Gemma was installed in her own home with her own support team.

Jan's list of memorable challenges included:

- the time of diagnosis when Gemma was 6 months old;
- her transition review at 14+ when it became evident that there was nowhere for her to go on leaving school;
- the fight to get a lighter weight wheelchair - resulting in the label 'difficult parent';
- going to court when her Statement of Special Educational Needs was withdrawn at the age of 16, and being excluded from the tribunal;
- the help provided in the home being untrained.

Jan went on to ask "what is a partner?" and concluded that it is 'a person associated with others in which he/she shares the risks and benefits.'

She then described the process of preparing and acquiring Gemma's own home which she now shares with her friend, Katy. At the beginning, parents of both girls thought about the future and what the girls wanted. They wrote a vision for Gemma and Katy which included:

- to live together locally;
- to have a bungalow with a garden;
- to have a place where family and visitors would be welcome;
- to be independent;
- to have a good team of staff to support them.

Gemma has her own Essential Lifestyle Plan.

When they were choosing the housing they considered where it should be, how big, whether to buy or rent, how to pay, could they raise a mortgage, how to redesign it to meet the girls' needs.

Many things had to be considered when choosing the support team. A specification was sent to the agency, and Gemma and Katy had a say on the interview panel. Challenges in recruiting and appointing staff included equal opportunities issues in recruitment, making roles and responsibilities clear, and providing induction for staff. Jan referred to the frustrations of changing staff, and having to start all over again.

The move was planned carefully, and involved trusting others implicitly. Jan admitted to having cold feet at the time. There are seven members of staff, not all full-time, and the cost is currently about £127,000 for the two together. The move has been a success, and Jan ended on a positive note by saying that *partnership assumes collective responsibility, and there is always a solution if we work at it together.*

In the afternoon session, Penny Lacey of the University of Birmingham facilitated a discussion around *Family Involvement in the Adult Years* in which a number of issues were raised including:

- The vulnerability of parents at transition to the adult world, and the need for a keyworker to support the family and guide them through the services.
- The different forms of relationships which have to be considered - professionals and families; families and children; professionals and professionals; professionals and people with PMLD.
- The importance of communication (and attitudes).
- The importance during transition of information, inspiration, and empowerment.
- Circles of support.

In considering the way forward, a number of suggestions were made for action to facilitate change:

- Person Centred Planning for carers (Family Centred Planning). Parents and their needs 'get lost' in the process. Their vision for their life is destroyed. Their value as supporters must be recognised.
- The support of a family mentor;
- Funding for Partnership Courses for family training;
- Supporting parents to be champions for their children;
- Partnership boards - as champions for a people with PMLD;
- National network of 'interested' people willing to give support in particular instances.
- The importance of celebrating achievement.

Professor Barry Carpenter concluded the seminar with a summing up of the day's discussions.

news.....news.....news

NEW RESEARCH GRANTS FROM THE FOUNDATION FOR PEOPLE WITH LEARNING DISABILITIES

The Foundation for People with Learning Disabilities (FDLP) announced in August that it will fund four two-year projects designed to help to meet the mental health needs of young people with learning disabilities. The grants coincide with a FPLD Inquiry into the subject, and are funded by *Baily Thomas Charitable Fund*.

All the projects are unique, and will provide models of good practice that can be disseminated and replicated throughout the UK. The projects involve the views of young people with learning disabilities, in some cases focus on minority ethnic groups, and address depression and anxiety.

The Foundation aims to influence future policy and practice in addressing the mental health needs of young people with learning disabilities, a severely neglected area.

Said Hazel Morgan, Head of the Foundation for People with Learning Disabilities: "I'm delighted with this grants programme. These projects are immensely promising, and we look forward to the results. Adolescence is a time when everyone is at greater risk of developing mental health problems, but young people with learning disabilities are even more at risk."

The projects are:

The implementation of self-defined service models via a liaison worker in a multi-ethnic inner city population.

Grant Holder: Dr Raghu Raghavan, School of Health Studies, University of Bradford.

The project focuses on the needs of young people from a minority ethnic community where language and cultural differences can create further barriers to getting the right services.

'What's Happening?' How young people with learning disabilities and their parents/carers understand anxiety and depression.

Grant holder: Alastair Wilson, Strathclyde Centre for Disability Research, University of Glasgow.

The project aims to examine user perspectives in a difficult area.

What leads carers to identify changes in emotional and mental wellbeing in young people with profound and multiple learning disabilities and how do they respond?

Lead Applicant: Professor James Hogg, White Top Research Unit, University of Dundee.

The study will look at how carers respond to changes in emotional and mental wellbeing and include workshops to help carers seek appropriate advice.

'Mind the Gap': research into meeting the mental health needs of young people with learning disabilities in Somerset working through the Connexions Service.

Lead Applicants: Paul St Quintin/Pauline Heslop, Joint Commissioning Team, Taunton Social Services working with the Norah Fry Research Centre.

The project aims to identify and overcome the barriers to service provision for young people with a learning disability and mental health problems making the transition to adult services.

For more information contact:

Anna Olek/Celia Richardson/Linda Steele

The Foundation for People for Learning Disabilities

Tel: 020 7802 0312 / 0313 / 0314 or, out of hours, 07721 587643

email: crichardson@mhf.org.uk

aolek@mhf.org.uk

www.learningdisabilities.org.uk

NEW EDITOR FOR *SLD EXPERIENCE*

Beryl Smith has retired as editor of *SLD Experience* and the new editor is Dawn Male who many readers will know in her capacity as Senior Lecturer in the Special Educational Needs department of the Institute of Education, University of London.

CHARTER OF RIGHTS FOR OLDER PEOPLE WITH LEARNING DISABILITIES AND FOR OLDER CARERS

Older people with learning disabilities and their carers need new rights to end their 'neglected minority' status, said the Foundation for People with Learning Disabilities.

The Foundation is launching a *Charter of Rights* to give older people with learning disabilities and older family carers flexible health and social care services, help in planning for the future and better information and support.

The Charter appears in a major report, *Today and Tomorrow*, launched on 17th October, which highlights the work of the foundation's *Growing Older with Learning Disabilities (GOLD)* programme. The report covers a range of different issues, research projects and services for older people with learning disabilities.

The Foundation recognises a growing awareness, in central and local Government, of the needs of older people with learning disabilities and older family carers who look after them. But, it argues, more must be done to meet those needs.

The life expectancy of people with learning disabilities has increased in recent decades. This means they are more likely to have age-related health problems, and to outlive their parents. The Foundation estimates that, of adults with learning disabilities living in the family home, 40% live with carers over 60.

The *Charter* states that older people with learning disabilities must:

- have the right to be supported in leading full lives, making and keeping friends and keeping in touch with families if they leave home;
- have access to services that are flexible enough to meet their changing needs as they grow older, and that respect their cultural, ethnic or religious needs;
- be able to choose where and with whom they live;
- have good health services, including screening for heart disease and dementia, and have their wishes respected, if terminally ill.

The *Charter* also states that older carers should have a right to practical and emotional support, including information and short breaks, and independent advocacy. From the age of 60, they should be offered help in planning ahead, with those for whom they are caring. Government policy in England currently prioritises carers aged 70 and over for such assistance.

Hazel Morgan, Head of the Foundation for People with Learning Disabilities says: "Our charter enshrines the rights that older people with learning disabilities and older family carers need and deserve to live their lives to the full in the 21st century."

While we know that policy makers and service planners are well-intentioned, change of this nature shouldn't depend on good intentions. That's why we're calling on those working with people with learning disabilities to adopt our charter as a starting point when planning services for people with learning disabilities and older family carers.

There are pockets of good practice - some of them funded by the Foundation and outlined in our report, *Today and Tomorrow* - and we can all learn from these. But there are still many areas where people face disrespectful attitudes and insensitivity, inadequate services or no services at all. This has to end."

Separate chapters cover friendship and how services can help create and support friendships among people with learning disabilities; health care, including interviews with women with learning disabilities about their experiences of the menopause; older carers, including practical steps for staff to take in helping families plan for the future; housing, including research on how to secure the family home for a person with learning disabilities; dementia and Down's syndrome, including issues and ideas for service providers; terminal illness and death, including the results of research into what makes a 'good' death.

A Charter of Rights for Older People with Learning Disabilities and for Older Family Carers

The Foundation for People with Learning Disabilities calls for older people with learning disabilities to have the right to be supported to:

- develop person-centred plans to meet their current and future needs;
- develop and maintain new friendships;
- maintain links with their families when they have left home;
- lead full lives with activities of their choice both during the day and also at evenings and weekends;
- have choices about where they live and with whom;
- have access to services which can adapt to their predictable age-related needs, both with respect to staffing and to their environment;
- have access to independent advocacy;
- have their physical and mental health needs met. They should have access to regular health check-ups, screening (including screening for the early onset of dementia if they have Down's syndrome) and to prompt treatment if they become ill.
- have their religious, cultural and ethnic needs respected;
- be cared for in terminal illness, as far as possible in a familiar environment, in a way that respects their wishes.

The Foundation for People with Learning Disabilities calls for older family carers, whose lives have been defined by their caring role, to have the right to

- :
- receive the practical and emotional support they require to continue to care for as long as they and their family member who has a learning disability wish.
 - support should include the provision of information, short-term breaks and access to support groups.
 - be given the peace of mind that the needs of their family member who has a learning disability will be met when they are no longer able to care full-time or after their death. This means that planning needs to take place over a period of time and at the pace that the family wants, when a family carer reaches the age of 60.
 - have support in their caring role. Their family member with a learning disability should have access to a range of activities outside the family home or additional support within the home according to individual preference.
 - have access to an independent advocate.
 - have their religious, cultural and ethnic backgrounds respected.

The Foundation for People with Learning Disabilities is part of the Mental Health Foundation.

Foundation for People with Learning Disabilities
Tel: 020 7802 03112
www.learningdisabilities.org.uk

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

Valuing People with Profound and Multiple Learning Disabilities (PMLD)

Written by the PMLD Network

Published by Mencap 2002

PMLD Network is a group of organisations, charities, professionals and parents who are working together to make things better for children and adults with PMLD and their parents and carers. In the wake of the Government's published white paper '*Valuing People*' they came together as a group to respond to the proposals and ideas from the standpoint of children and adults with PMLD who are so often overlooked. This report sets out very clearly how the ideas in the White Paper can be made to work for children and adults with PMLD, their families and carers.

The introductory section makes it clear that the Government's White Paper has raised important issues which are relevant to people with PMLD but that the range of initiatives will only reap benefits for this group of individuals in the context of a far greater consideration of all the issues which confront children and adults with PMLD, their parents and carers. *Valuing People* has failed to move the needs of this group higher up the government agenda. This report makes the recommendation that in order to facilitate this there should be a champion who can focus on the needs of PMLD within the Learning Disability Task Force and Local Partnership Boards should also represent people with PMLD as a matter of course.

The report highlights the longstanding ignorance and confusion about who this group of people are. *Valuing People* is itself inconsistent in the use of its terminology. The PMLD Network are emphatic that there must be clarity about terminology and definition in order that the population of children and adults can be counted and thereby allowing their needs to be more fully understood.

The report has nine chapters in all with a further summary section of all the recommendations being put forward at the end of each chapter. The chapters are very readable and concisely set out bringing together a combination of the problems and challenges facing children and adults with

PMLD along with a number of examples of good practice and new ideas which, if implemented would raise the profile of children and adults with PMLD. The Report is adamant that people with PMLD need to be seen as a priority if they are to benefit from what extra resources are to be made available to effect change. So often agencies stand by their policies that limited resources should be shared amongst the needs of many rather than focusing on the needs of the few with the consequence that the needs of people with PMLD are often overlooked and because their needs are multiple and complex, they are not able to access the services of 'one hat fits all' system.

The final chapter of the report is called 'Making Things Happen' and shares with the reader a beautiful picture of a vision for the future. It is an account of Katy and Gemma's story. Both girls have profound and multiple learning disabilities but thanks to the indefatigable determination of their parents, Jan and Wendy, are now tenants of a large specially adapted bungalow living with the support of a team of helpers. They have essential lifestyle plans which are regularly reviewed and updated to ensure that they are able to continue to lead the lives they choose. The story demonstrates that things can happen with a huge amount of patience, determination and perseverance to champion the cause. Why aren't we surprised that it was the parents who were and still are the champions?

This report is essential reading for all working in the field of learning disability and those who see themselves as champions of children and adults with PMLD. I hope that this excellent response on behalf of people with PMLD by the Network marks the start of raising the needs of children and adults higher up the whole nation's agenda.

Julia Dixon
Parent

BOOKS AND RESOURCES

Valuing People with Profound and Multiple Learning Disabilities (PMLD) produced by the PMLD Network. Report written in response to the government's White Paper 'Valuing People' making clear how ideas in the White Paper can work for children and adults with PMLD. Copies available from Beverley Dawkins tel: 020 7696 5558

Good Practice in Citizen Advocacy written by John Brooke. Guidelines which support citizen advocacy schemes in establishing, evaluating and maintaining quality, and which make available a wide range of experience and good practice developed by citizen advocacy schemes across the country. Published by BILD Publications - tel: 01752 202301

Working Towards Inclusive Education: Social Contexts by Peter Mittler. Published by David Fulton 2000. ISBN 1 - 85346-698-0

Advocacy and Learning Disability edited by Barry Gray and Robin Jackson. Jessica Kingsley Publishers.

Working Together? Multi-agency working in services to disabled children with complex health care needs and their families: a literature review by Debby Watson, Ruth Townsley, David Abbott and Paula Latham. Report of the first phase of a project exploring joint working for children with complex health care needs, their families and the professionals. Published by Handsel Trust 2002 e-mail: handsel@LineOne.net. ISBN 1-903745-04-7

Approaches to Communication through Music by Margaret Corke. Approaches and activities devised to promote the development of communication and social interaction at a fundamental level. Published by David Fulton 2002. ISBN 1-85346-843-6

Access to History: Curriculum Planning and Practical Activities for Pupils with Learning Difficulties by Andrew Turner. Access to the history curriculum for pupils with learning difficulties with guidance on the P levels; assessment and recording; teaching history in a cross curricular way. Published by David Fulton. ISBN 1-85346-857-6

Access to Citizenship: Curriculum Planning and Practical Activities for Pupils with Learning Difficulties. by Ann Fergusson and Hazel Lawson. An inclusive framework of participation and achievement for all including a range of activities; reference to the P levels; assessment and recording; whole school and community approach. Published by David Fulton. ISBN 1-85346-910-6

Access to Science: Curriculum Planning and Practical Activities for Pupils with Learning Difficulties by Claire Marvin and Chris Stokoe. Support and ideas for effective planning and implementation of science-focused activities including early years and all key stages; developing skills through sensory science; progression in curriculum content and experience; assessment and recording. Published by David Fulton. ISBN 1-85346-917-3

Everyday Lives, Everyday Choices for people with learning disabilities and high support needs produced by Foundation for People with Learning Disabilities tel: 020 7802 0304

The MOVE (Mobility Opportunities Via Education) Curriculum (European Edition). Educational programme to help learners with severe disabilities to sit, stand and walk focusing on functional skills which will lead to greater independence. Available from MOVE Europe tel: 020 7414 1493

The MOVE Assessment Profile. For use in conjunction with the MOVE Curriculum. The profile can form part of Individual Education Plans and Therapy Outcomes. Available from MOVE Europe tel: 020 7414 1493

Using My Life and *My Life* developed by the Quality Network (BILD and National Development Team). These materials are designed to be used together to assess and improve services and inform individual planning. Available from BILD tel: 01752 202301

COURSES AND CONFERENCES

OCTOBER

20th Rehab and Care
and Venue: NEC Birmingham
21st Further details: 00870 429 4372

DECEMBER

3rd Cultural Issues in Sexuality Work with People with Learning Disabilities
and Exploring different cultural attitudes towards sex education and people with learning disabilities within services, and practical implications of carrying out sexuality work with service users from a range of cultural backgrounds within an equal opportunities framework.

4th Organised by: Consent
Venue: Harperbury, Herts
Led by: Seema Malhotra
Further details: Consent
Tel: 01932 670796/670804
e-mail: consent@hnhsoc.demon.co.uk

31st SPECIAL NEEDS LONDON - Exhibition
Nov. 1st Wide range of resources and equipment
and 10th Special Educational Needs Book Awards
2nd Seminars on a variety of subjects including:
Developing Inclusive School Practice
P Levels - The Way Forward?
Using QCA Performance Descriptors (P Levels)
Best Practice in Teaching Pupils with PMLD
Further details and registration:
The Publishers Association
Tel: 020 7691 9191
www.publishers.org.uk/special needs

NOVEMBER

6th Multi-Sensory Referencing including Objects of Reference
Introduction to a set of techniques that help individuals to make sense of their world. It includes Sensory Cueing and use of Objects of Reference.
Organised by: Sunfield Professional Development Centre
Led by: Tony Jones, Liberator
Venue: Sunfield PDC, Stourbridge
Further details: Administration Office, CPDC
Tel: 01562 883183
e-mail: sunfield@sunfield.worcs.sch.uk

16th Making Inclusion Work for Pupils with Severe and Profound Learning Difficulties
Good practice and innovative approaches that provide relevant inclusion opportunities for children and young people with Special Needs.
Organised by: Briarwood and Whitefield Fishponds Community School
Venue: Bristol
Further details: Tony Letts
Tel: 0117 965 4536
e-mail: briarwood.school@talk21.com

26th Using Handling Resources
Part I - for staff who work with adults with learning difficulties to introduce Tate Britain's handling resources which can then be borrowed to support independent visits or in preparation for:
Part II - a chance to trial the resources and activities with a client, assisted by Tate staff.
Venue: Tate Britain
Further details: Sharon Trotter
Tel: 020 78887 8769
e-mail: sharon.trotter@tate.org.uk

DECEMBER

5th Intensive Interaction
Introduction to using personal qualities of face, voice and body language to involve the learner in progressive sequences of interactive activities.
Organised by: Sunfield Professional Development Centre
Led by: Dave Hewett
Venue: Sunfield PDC, Stourbridge
Further details: Administration Office, CPDC
Tel: 01562 883183
e-mail: sunfield@sunfield.worcs.sch.uk

9th Three day Induction Course
Understanding 'Challenging Behaviour'
Led by: Tim O'Brien

10th Enabling Communication in Children with Severe and Complex Needs
Led by: Mandy Addenbrooke

11th Curriculum Development
Led by: Prof. Barry Carpenter
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

2003

JANUARY

30th Exploring Sexuality Issues for People with Profound Learning Disabilities
and Using recent research in this area the course aims to develop staff confidence to
31st ensure that this complex area is considered and ways forward are identified to support individuals in a sensitive way.
Organised by: Consent
Venue: Harperbury, Herts
Led by: Christina Paparestis
Further details: Consent
Tel: 01932 670796/670804
e-mail: consent@hnhsoc.demon.co.uk

JULY

10th Sherbone Developmental Movement - Level 3
to Three day residential course
12th 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

BILD Workshops and Conferences

These cover a wide range of topics including:

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

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

OPEN DAYS

Action for Leisure Resource Centre Open Days:

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

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

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

Wednesday 6th November

Friday 15th November

Tuesday 10th December

Booking form from:

Action for Leisure, C/O Warwickshire College, Moreton Morrell, Works CV35 9BL

Tel: 01926 650195

e-mail: resources@actionforleisure.org.uk

www.actionforleisure.org.uk

LONGER COURSES (with accreditation)

Interdisciplinary work with People with Profound and Multiple Learning Disabilities

A one year distance education course for practitioners and carers of children and adults with profound and multiple learning disabilities. The main focus is upon lifelong learning, communication and effective interdisciplinary collaboration.

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

University of Birmingham School of Education

Further details: Sandra Cumberworth Tel: 0121 414 3466

M.Sc/PG Diploma in Learning Disability Studies

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

This course meets the training needs of a variety of professionals involved in delivering services to children or adults with a learning disability, including registered nurses, social workers, doctors, occupational therapists, physiotherapists, speech and language therapists, officers in statutory, voluntary or private establishments, FE tutors, staff of SECs. It provides the opportunity to participate in and contribute to inter-disciplinary learning in a collaborative setting.

Further details: Helen Bradley, 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: JTIOffice@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