

PMLD**LINK**

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

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

EDITORIAL

In this issue most of the articles are written by parents - and we are really grateful to you all for writing for us. Some articles are very moving accounts of personal experiences, one is about how a parent has become involved in developing services. Although two of the articles are not actually written by parents, parents are very much at the heart of the services described, both of which are very different.

Many thanks of course to all those who sent in other contributions - reports of conferences, news, information about projects, books, resources etc. which, we hope, makes PMLD-Link a valuable source of information.

If you are researching a particular topic, or have any information that you think other people would like to share, do write in with a letter or article about it. And please do respond to the requests for help which people send in - if you work in further education, Deanna Davies who has asked for help in this issue, would like to hear from you.

Future Focus

Few people would not agree that creative activities are an important aspect of life, and that they can be a particularly effective way of communicating with people with PMLD. The next issue is about creative activities, and in our discussions about this topic the editorial team were very conscious of the issues around movement and physical management involved in both creative movement activities and in accessing other forms of art activities. With the regulations on lifting and handling, and the need for input from physio- and occupational therapy, the problems can be difficult to overcome, and this may prevent some people who have physical disabilities from being able to participate in activities which they would otherwise enjoy.

Do write in with your experiences of creative - or any other activities, and let us know how the children or adults you work with or care for managed to participate. Any other articles on creative movement or ways of accessing activities, whether creative or otherwise, would also be interesting.

Business Matters

Subscriptions - this is the time of year when subscriptions need to be renewed for 2002, and unless you have already done so, you will find a subscription form with this issue. Subscribers in the Republic of Ireland should renew through Rosaleen O'Halloran, our Ireland co-ordinator, as usual. We hope that this makes it much easier for you to pay your subscriptions.

Articles - on the 'theme' or on any other topic at all - should be sent to me by the end of February 2002. Send them by post or e-mail (Rich Text Format please) to:

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How was it for you? A mother's journey

A year ago I was in a mess - not a neat puzzling maze where you know you'll work it out, but a basin of dark sticky mud where you thrash around feeling ever more useless.

Until Darren (my son with Down's Syndrome, and severe learning disabilities) was 14, we were his life and he was ours - a small demanding child amongst demanding brothers and sisters - and we were strong. And then it changed. Every piece of our jigsaw changed, just a little, and then the pieces didn't fit together any more. Darren got stronger, and angrier. Andrew, his father took a stronger role - and angrier. The children became teenagers and found ways to avoid us. I got lonely, and tired, and watched my family fall to pieces.

Social Services were slow to help. Looking back from a sunnier place I can say that the awful cycle of waiting and writing and phoning did play an important part - in building up their knowledge of our needs, and in identifying those needs to ourselves. Of course I did think at the beginning that one call would bring in the cavalry - it took longer.

In May 2000 we had experienced one respite carer who could have Darren for four weekends per year! And another who loved him dearly but was busy until July. We also had one strong cross untameable child who had made his presence felt so strongly that not one driver from four companies would take him to or from school. We demanded emergency meetings. The Careers Advisor knew of one school for Challenging Children which I visited - trying really hard to see why I needed this. Beds and chairs of breezeblock and cement, covers of plastic and urine, carers with bunches of keys etc. etc.

That first school was the kick start I needed. With a phone call from the LEA Officer: 'you have no authority to make these visits', I set off to find a real school: one that would offer a good residential education for my son.

I knew the Meadows was the one, when I first drove up past the goats and donkeys, as the children from Bracken were having a waterfight on the sloping terrace! Over two visits we were able to explain, rant, cry, adjust, see every class and house, talk to the Principal and lunch with the students. After years of defending Darren and being his carer and conscience I developed an overwhelming sense of betrayal, telling tales, but the tale had to be told. I'd kept a lid on it, but once the lid was off it wouldn't go back on.

Someone else's son had a major outburst while we were visiting, it was very refreshing to see the staff deal with the problem and still smile at us over their shoulders: 'Excuse us a minute!' I couldn't wait to ask 'will you phone his mum? Tell the Head? Send him home?', 'Goodness no' this isn't really a problem' - wonderful!

A long desperate haul from there to November - hard to remember when. Crying on the phone, crying when I couldn't get Darren upstairs, or into his clothes, when I had to take him to work with me. I had a nasty letter from a driver: 'why did I expect everyone else to solve my problems' - painfully true. But they did.

Darren had a leaving party at his day school and moved to The Meadows the next day, November 18th.

How was it for me? Awful! Brilliant!

The guilt. What kind of mother sews labels in her boy's pants and sends him away? Horrified. Selfish. Want a child, don't want a child. Betrayal. 'Well you did your best for him' - but never enough.

Darren in his big sunny room in Birch, surrounded by new friends who've come in to see who he is and what's in his bag. Friendly staff who give you space but come if you want them. Arriving again in December to find everyone jumping and singing, and a Christmas tree in Darren's room 'because he wanted one'. Christmas Open Day, all the children valued, for the first time in 15 years he's not the clown, the bad boy. He's a successful child among successful children, in a Meadow School sweatshirt. Rescued. Relieved. Justified. Right.

Brilliant - being abler to move freely around the site. Home, receiving messages of support from the Family Worker and phone calls and letters from Darren's carers, so often that it feels like family.

A few weeks ago I couldn't look back without feeling that cold dark shadow very near, I couldn't face Darren's photo in the mornings. But now the diary is filling up with Darren's new life, review and open day, weekends and concert, hair cut, new shoes. So I haven't given Darren up, I've done him a favour! He's having the best possible time and I'm still his mum. The Head once said 'Hang on. It will get better'.

Yesterday it did. - We drove back to The Meadows on a crispy sunny morning. Darren and his brother jumped out of the car and ran up the drive together, they couldn't wait to see his room again, and they were laughing. How was it for me? Just fine thankyou!

A relieved Mother

The name of the school and family members have been altered in this article.

Reflections of a Parent

Our eldest daughter, Victoria, will be 18 next week. I can hardly believe it because in many ways the time has passed by so quickly. Victoria was born just a few weeks early in August 1983 but became very poorly after the first few hours and spent several weeks in the special care baby unit. I can remember it all as if it was yesterday.

The first few years of Victoria's life were punctuated with hospital appointments, illness and many stays in Derby Children's hospital (usually for chest infections). Shortly after Victoria was born (by undiagnosed breech with forceps) we were told that she had CDH (congenital dislocation of the hip) and she would need to be fitted with a special splint as soon as possible. When I reflect on all that was happening then I realise how little I understood and the major impact the little bundle was going to have on our lives. I recall with horror a consultant paediatric neurologist replying during a consultation when I innocently asked him if he thought Victoria would learn to say any words "Good God woman, she'll never talk" at which point I promptly burst into tears. (He did at least pass me a tissue).

I remember listening to Professor Barry Carpenter at a conference on Babies and Families a couple of years ago saying "there is no good news" when you find out you have a child with special needs. The words struck a very deep chord within me. It's not that Victoria isn't truly lovely and a great joy but she wasn't what we were expecting. Good news has been scarce but we have always had hope. Victoria was eighteen months when the pain and anxiety of not knowing why her development was so severely delayed came to an abrupt end. We were told that an abnormality on Victoria's chromosomes had been discovered (22q13) and the absence of genetic material on the long arm of chromosome 22 was the culprit. No other recorded case, no information, just a wait and see game.

So here we are at Victoria's eighteenth birthday. We have waited and we have seen that with all her beauty and crowning glory of blonde hair, Victoria has grown up with a profound learning disability compounded by very severe communication difficulties and cerebral palsy.

Being a parent to any child is a challenge only more so when your child has a complex disability. The sad truth is that I am not alone when I say it's a struggle. Many of the readers will also be parents and know that only too well. There is an inborn instinct as a parent to want to try to do the best you can for your children. When your child has a disability the whole process is so much more difficult. There are so many people involved, so many decisions to make, hospital appointments to keep, reviews to attend, benefits to apply for - the list could go on and on.

I would agree with many who have often likened learning that your child has a disability to bereavement, but only in that there are similarities.

There are stages of grief, anger, possibly resentment to pass through before coming to terms with it and reaching a state of final resolution. However after years of parenting Victoria I would now say that coming to terms with your child's disability is just the beginning. In my experience things never really settle down completely. I have found that the grief continues to surface from time to time. I remember when Victoria was eleven and about to make the transition from an SLD primary school to an SLD secondary school feeling an overwhelming sadness as friends became excited about their children moving up and on from junior school to start their secondary phase of education and make their first steps down that road which ultimately leads to independence. The old scars of the wound do become inflamed and sore from time to time. Once the unsettling phase has passed, life establishes new routines and patterns until the next problem, crisis or decision looms, be it major surgery and set backs which the latter entails, or the dreaded transition planning for life after school.

The current situation for Victoria's future is still uncertain. A few years ago, when we seemed to have a lot more energy than we do today, we considered very seriously setting up a long term home for people with learning disabilities as a way of ensuring future life long provision for Victoria. I admire anyone who has been able to do this, but it's unbelievable how a simple vision of a small community for people with learning disabilities is in reality such a very complex business. We had to consider the needs of the whole family and with three younger children we had serious misgivings about whether it was the best way forward for us. A few years on with hindsight I think the idea of starting a community was a solution for me to ensure that Victoria would be well looked after and continue to develop to the best of her ability as at that time I was full of doubts that I would be able to entrust her to anyone else's care.

I remain hesitant but resolved that in Victoria's best interests she needs to move on to a long term home where she can lead a fulfilled and happy life, but retain close links to us all. The responsibility of going along this route is awesome and emotionally draining. Endless meetings and discussions, care plans, assessments, hopes raised and then dashed by yet more bad news "We don't feel that we would be able to manage Victoria's needs within the staffing that we have" is a fairly typical response.

Fortunately Victoria has an August birthday and so she can stay on at her school until she is nineteen which buys us some more time to find a suitable place for her to move on to. You never know what's around the corner and we may well start that Community one day. For this evening, I shall enjoy some precious respite while Victoria is enjoying a barbecue at the local respite hostel in Ashbourne and the other girls are camping with the much beloved in Dorset.

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Gemma's Story

Gemma has cerebral palsy, learning difficulties and quite complex needs. She is now 21 years old and lives in her own home supported by care staff 24 hours a day. What follows is a brief description of a few of the milestones we have encountered on the way to where we are today.

In the beginning ...

Gemma is my only child. She was delivered ten weeks prematurely in a small cottage hospital and weighed 2lbs 4ozs. I was not allowed to see her for the first three days and by the time she was five days old she was admitted to her third hospital and second Special Care Baby Unit. It was not an auspicious start. At five weeks I was allowed to hold her for the first time and when she was almost three months old and all of 4lbs 8ozs I was allowed to take her home.

I myself am the youngest of five children and although I have a nursing background none of it was in paediatrics or midwifery. It was soon clear that all was not right. I had to fight hard to establish that I was not an over anxious mother with unrealistic expectations and it was only with some persuasion I was able to secure an appointment for a paediatric neurological opinion at the Royal Hospital for Sick Children in Glasgow. After a very short initial consultation I was told that Gemma had cerebral palsy, that she would be unlikely to walk independently and that she would certainly never receive 'normal' education. In fact Gemma has severe learning difficulties which are further complicated by a serious high tone deafness. Since the age of ten she has had complex partial epileptic seizures. I was entirely devastated and 'coped' in the initial period by blanking out the interview entirely and confiding the news to no one, until I had been able to come to terms with it myself. After 21 years I am not at all sure if I have managed this. What I am sure of is that it was essential for me to seek out as much help and information as possible in order to acquire a greater understanding of my daughter and her needs.

The way forward ...

The biggest single lesson I have had to learn has been to let go, in order that Gemma can lead as normal and independent a life as possible. At every stage in the process that has brought us to where we are today and I have acquired information from many sources. Whether it has been to identify a suitable nursery, school or college placement, or the right accommodation to meet her needs for now and the future, information is the key. For the most part I have received good advice and support from staff employed in these placements, as well as other parents in similar circumstances. I have had many discussions with the 'professionals', be they medical, educational or social services based, but it boils down to the fact that I am the expert on Gemma and they are the gate-keepers to accessing what she needs. In working with some professionals less than productive relationships have existed, but in many instances I have had to disregard my own feelings in order to get what is in my daughter's best interests.

I have never been reticent about putting things in writing and I have several rain forests lurking in my loft to testify to this! Copies of correspondence relating to key issues have been forwarded to senior representatives of the Social Work Department (Social Services Departments in the rest of the UK) or my local councillor, or the Member of Parliament, whoever I thought most appropriate.

I have pursued an official complaint, where I feel it was justified, and I have approached the Court of Session in Edinburgh to secure additional rights, which I think will help to safeguard Gemma over this period of transition. We have used newly enacted legislation in order for her to be allowed to buy her own house with a mortgage from the bank of Scotland. Finally, in September 2001, Gemma moved into her own home, supported by an individual package of care, covering 24 hours per day, seven days of the week from an excellent team, whom she helped to select. Make no mistake, there can be no underestimating the considerable shift in attitude on the part of the local Social Work Department representatives that we have dealt with in recent years. However, these shifts pale into insignificance when looked at in the context of the realisation of so many hopes and dreams.

Conclusions

This is not the end of the story. It is really just the beginning for Gemma but perhaps it is the beginning of the end for me. Of course I am still going to be involved and even now we are looking into the possibility of accessing direct payments for Gemma to employ her own personal assistants in the future, when the time is right. What I think is important is to reflect on what we have achieved to date:

- Successful cases were made for preferred primary, secondary and even tertiary educational placements.
- The granting of Tutor Dative* status to myself, and my sister, in order to safeguard Gemma's interest over the major transition period to full adulthood.
- A Trust Deed will come into place after my death to further safeguard Gemma's interests.
- Successfully secured an individual package of care for 24 hour per day, seven days per week, 52 weeks per year.
- Gemma has been able to buy her home, with the help of a mortgage from the Bank of Scotland. By using new disability Scottish legislation Power of Attorney was granted to me in order, amongst other things, to enter into legally binding contracts on her behalf.

In summary

I firmly believe that what we have in place is a testament to Gemma's strong will, determination and unique personality. Through careful planning and preparation it means that one young woman, who happens to have quite complex needs, is able to lead a life that is more full and independent than we could ever have envisaged. If I have any advice to pass on to others it would be this:

- Communication and dialogue is the key to a successful outcome.
- It is imperative to gather as much information from as many sources as possible - but keep an open mind throughout the exercise.
- Be clear about what you want and why.
- Be prepared to stick to your guns.
- Don't be afraid to get help from your elected representatives.
- Retain all letters and send copies of correspondence to those who have an interest in the outcome.
- Never give up hope.

Gemma has been able to realise her dream and I feel that there should be no barrier to others who wish to be just as fulfilled.

Eileen Low

Parent member PAMIS, Glasgow

* Under Scottish Law application is made in the Sheriff's Court for the status of Tutor Dative. The Tutor Dative can apply for a number of powers, e.g. Power of Attorney, and the right to take major decisions (such as medical, financial, social and housing) on behalf of another person. The Tutor Dative is not necessarily a relative.

Our New Scottish Consortium for Learning Disability

The same as you? review of learning disability services in Scotland

On May 11th 2000, the Scottish Executive (our Parliament) launched its review of services for people with learning disability. *The same as you?* White Paper contained a number of recommendations and one of these was that "the Scottish Executive should set up a new Scottish Centre for Learning Disability." This would offer advice, training and support to anyone involved with, or who has an interest in learning disability, people with learning disability themselves, their parents and carers. The new centre would also have a role to see that the many changes to services recommended in *The same as You?* report. Last year, 13 organisations involved with learning disability - voluntary organisations and University research departments - joined forces to put a bid to the Scottish Executive to set up the centre. Their bid was successful, and the centre became a reality! I and many other parents (through our involvement with *PAMIS*) had been involved from the outset with the review of learning disability services. We attended consultation seminars, were members of working groups and contributed to roadshows throughout Scotland during 1999. I also attended the official launch of the Report with my son, Craig who has profound and multiple disabilities. The conference to launch the white paper was led by people with learning disabilities and their carers. Using multi-sensory storytelling techniques, Craig gave his response to the review alongside his peers.

SCLD: The role and responsibilities of a Trustee

Earlier this year I was honoured to be invited by *PAMIS* to be a Trustee of the new centre, and accepted the position with great enthusiasm but also with some trepidation at the responsibility given to me. One of the first tasks that had to be performed was to interview and employ the main individuals who would run the centre. These would be a Director, Assistant Director, and a Co-ordinator. I was asked to be on the interviewing panel to represent *PAMIS*, and the needs of people with profound and multiple learning disabilities. It was a difficult task, with so many talented people to interview, but very rewarding as in the end I am confident that we have employed three highly skilled, wonderfully motivated professionals to lead the centre. The Board of Trustees is made up of two representatives from each of the 13 member organisations and agencies. Trustees include people with learning disabilities, parent/carers, professionals, and academics, this composition demonstrates that we are truly inclusive. One of our first decisions was to change our name to the *Scottish Consortium for Learning Disability (SCLD)*.

How the SCLD will work

We have set up four specialist committees each with a remit to deliver key tasks. The committees are Research, Training, Public Education, and Information. I have involved myself in the Research Committee as a *PAMIS* representative, because people with profound learning disabilities need to have a voice in setting the research agenda. The committee will mediate with the research bodies and funders to suggest research on issues that are relevant, or of importance to their lives and well-being and will involve people with learning disabilities and their carers.

National Scottish Network on PMLD

PAMIS have also been given responsibility for setting up a national network on profound and multiple disabilities. The aim of this network is to bring together parents and professionals with an interest in PMLD throughout Scotland to work to improve information, develop and deliver training on all aspects of profound disability. The network will establish, through e-mail, an information and queries exchange forum as well as organising seminars and workshops. A newsletter will also be developed which will disseminate up to date information on PMLD and will feature articles from parents and professionals.

Real opportunities to achieve change

Being a part of the SCLD - this new and innovative association of professionals, academics, carers, and people with learning disability in a timely inclusive environment is very exciting - because there will be genuine opportunities for making *real* differences to the lives of people with learning disabilities and their families. I will have the opportunity to advocate for people with PMLD as

their needs are often marginalised through being unable to speak up for themselves and there is also a real fear that these needs will be missed out in the sweeping changes that are now taking place in service development throughout the country. I will represent their needs, and those of their carers on the Board of Trustees. I am determined to support my fellow Trustees to achieve the aims of the Consortium, as set in the recommendations of our White Paper, *The same as you?* I believe I have been given a great opportunity, and will do my utmost to validate the trust and responsibility that has been given to me as a Trustee of the *Scottish Consortium for Learning Disability* and as an ambassador for people with profound and multiple learning disabilities. Of course I will not be a lone voice, as well as getting support from the members of the Board of Trustees, I will be calling upon the wide *PAMIS* network to ensure that the views of parents and professionals already involved in *PAMIS* are fully represented in everything I do as a member of the Consortium.

Jenny Whinnett
Parent member *PAMIS*, Grampian

*All means All: supporting people to be part of their community
The development of Inclusion Alliance,
an inclusive day service in Edinburgh*

Introduction

Inclusion Alliance is an organisation comprised of people with learning difficulties, parents and professionals, working together towards the inclusion of people into ordinary life. They provide one-to-one support to 13 men and women with high support needs. The organisation aims to enable people to lead the lives they, and the people closest to them, choose as active participants in their local community, by offering an individual and flexibly tailored support service for 31 hours a week.

Principles

Inclusion Alliance are inspired and guided by the principles of inclusion. We believe our communities will be better places for all of us to live in when people who, historically, were segregated into 'special' services are re-connected to the mainstream of everyday life. A person-centred approach is fundamental to how we support people as individuals, and how we plan with people. We use the Five Accomplishments as a guiding framework to help ensure we are supporting people to get the kind of life most of us take for granted. And, we are striving to be a learning organisation, aware that we are engaged in a long-term process of change and we do not have a 'blueprint' for what we are trying to achieve.

History

The organisation was formed through an alliance of parents and professionals. The parents belonged to a group called Parent Pressure, who formed with the aim of persuading the relevant authorities to provide better services, of influencing policy and changing attitudes through lobbying and informing Council Committees and the Scottish Executive. Parent Pressure were determined that they would not accept segregated services for their sons and daughters and formed an alliance with EDG (Edinburgh Development Group). EDG is an organisation experienced in asking people with learning difficulties and their families what they need and want and then trying to develop innovative and high quality services to meet these needs. Together, they approached People First, a local self advocacy group who were also seeking alternatives to Day Centres. Representatives from this group joined Inclusion Alliance in 1997 and this new organisation approached the city of Edinburgh Council Social Work Department for funding. The Social Work Committee, following their policy of promoting more inclusive services, were looking for proposals offering alternatives to Day Centres. They thus agreed to fund Inclusion Alliance for an initial one year pilot. Three and a half years on and we are still here!

The Council now provides core funding for a manager, a part-time administrator and 13 full time equivalent facilitators. They also provide each individual with a budget for expenses, transport and relief cover.

What is different about Inclusion Alliance?

We are a small organisation supporting 13 individuals. We share a commitment to finding ways of working together and learning how to make the values of inclusion and a person-centred approach real for people.

We are a user-led organisation which involves users and their families in decision-making at every level. Over half the members of our Board of Management are people with learning difficulties or carers.

The focus of the service is on supporting people to access mainstream places and developing opportunities for relationships and friendships between the people being supported and other community members. This focus on 'connecting' people back to the mainstream of everyday life means we look at how people can spend time with other people through shared interests and participation in community education, college, work experience, paid employment as well as leisure and social activities.

Each person has their own support worker, or Facilitator, who works just with them. We involve each person in the recruitment of their staff as well as their family or friends. The service is for people who require 1-1 support and who have previously been labelled as having complex or severe learning difficulties. Some people have 2 workers some of the time. We are flexible in when we support people, not being tied to a building with set opening and finishing times nor to special transport; people can choose to use their 31 hours a week support in the way that best suits them.

The support we provide begins and ends each day from the person's home. We do not operate out of a centre; people's homes are used during the day for those who need somewhere to go due to health or personal care reasons, and people's communities and city provide the 'base' for a community based lifestyle.

What helped us to succeed?

- A strong vision of what we wanted and the values and philosophy underpinning that.
- Research into ideas and projects that shared our vision and from which we could learn.
- Familiarising ourselves with Government and council policy and legislation to see where our ideas were compatible and to put together a proposal that would fit current thinking.
- A detailed and well thought out proposal.
- Networking - we found people who had influence and shared our vision, and cultivated relationships with them.
- Families who were clear about the kind of life they wanted for their sons and daughters and who were prepared to work in partnership with others making, on occasion, some difficult decisions to bring this about.
- Having staff with a clear sense of vision about what is possible and a strong commitment to making it happen.

What are we learning?

- The service design depends on the use of the individual's home as a base which can be accessed during the daytime. This is essential for those who require a high level of personal care or for those who need to rest from a seizure or just take some 'time-out'. The personal commitment from families and carers has been essential for this to work and this commitment has not been diminished by the inevitable niggles that have arisen from time to time.
- Families, facilitators and the organisation need to establish good working relationships and procedures. Some traditional ways of line managing or team working need to change to meet individual needs and circumstances.
- Supporting people to access mainstream places and activities for 6 hours a day and 5 days a week takes effort and planning. What helps is knowing the detail of what works and does not

work for each person, being creative and recognising that a fulfilling life evolves over time. Striking a balance between structure and flexibility is highly individual and requires agreement from all the significant people in the person's life.

- Staff are working on their own for much of the time and need to be comfortable working with a high degree of trust and able to 'self supervise' for much of the time. Maintaining motivation is crucial.
- Being person centred means there is not one model or one method of planning which works for everyone. We are continually learning from each person and those closest to them what is right for them.
- Some places and some individuals are not yet ready to welcome everyone. We recognise that we are involved in a long term process of change and we need to identify and work alongside allies who share our vision.
- Public transport is still often inaccessible, unreliable and limited. Consequently, transport for people with mobility difficulties is expensive and not always flexible. This needs to be taken into account when planning a service that aims to use existing community resources.
- Likewise, decent community-based personal care facilities are extremely limited. Having access to the person's home is essential.
- Relief cover is crucial to the proper operation of the service. Recruiting and retaining a pool of reliable relief workers has proved to be the biggest operational problem facing the organisation. In retrospect, we should have aimed to build in to the costs at least 2 extra workers as a fixed relief pool.
- We are only funded to offer a service for 47 weeks in the year. Many families have found it extremely difficult to access additional support for the other weeks.
- Facilitating real connections between the people we support and people in the community is taking a long time to achieve. It is therefore important to keep staff motivated and focused on the good things that are happening for the person now, as well as on longer term goals.

What are we learning about community connections?

- Using places on a regular basis can lead to connections.
- People are being seen as individuals with unique personalities and are being known by their names, missed when they are not there - this 'modest' achievement is a big step for people who may not previously have been known outside of immediate family and paid professionals.
- A lot of thought needs to go into how people are introduced and how any point of interest is nurtured and supported.
- The people around each person such as family, friends and staff using their own friends and networks is a good starting point.
- Some places, cafes, community classes and so on are not very welcoming and we need to keep looking for those that are.

What are we learning about circles of support?

- There are different stages of development and it takes years for a self-sustaining circle to develop.
- They will not work if key people in the person's life do not feel they are necessary or are not convinced about their effectiveness.
- The presence of a support circle does not itself guarantee innovation and vision, but without them, we need to identify different sources for the creativity and energy required to make positive things happen for the person.

What impact is the service having on the lives of those we support?

People have said

"She has made more contacts and friends than she ever would have at an ATC"

"He was a very withdrawn, unsociable, uncommunicative, anxious young person who has blossomed into a confident, outgoing talkative person willing to try new and varied activities"

"Individuals develop self confidence, are more alert and outgoing"

"The person is having less seizures because the service is more suited to her pace".

"People are becoming more confident in making choices - asking to see certain people or go to certain places".

"Seeing the people I work with enjoy their lives indicates achievement".

"Things change to suit the individual; this is an indicator of responsive, flexible individualised support".

"It offers people who are vulnerable the chance to become active citizens in their community".

"The language and attitude of members of the public is positive: they talk about how the person has impacted on their lives and changed their view".

Conclusion

We know we still have a way to go in assisting people to live lives truly of their choosing. We continue to question and evaluate what we do and continue to listen, learn and understand more deeply each person to whom we offer support.

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e-mail: john@edg-sco.org

Inquiry into the Mental Health Needs of Young People with Learning Disabilities

The Foundation for People with Learning Disabilities, part of the Mental Health Foundation has launched an Inquiry into the mental health needs of young people with learning disabilities. The Foundation is asking parents and families to write in if they have ever been concerned about that person's mental health needs.

It is estimated that 4 out of 10 young people between the age of 13 and 24 may have some form of mental health problem. The Foundation believes that learning disability services have tended to focus on practical rather than emotional issues, and wants to bring together the evidence that will change future services and practice.

The Foundation for People with Learning Disabilities is asking for information by 4th March 2002. Any families wanting to contribute to the Inquiry can find more information on the Foundation for People with Learning Disabilities' website www.learningdisabilities.org.uk : 020 7535 7437

Training for Families - Celebrating Diversity

The information needs of parents of children with disabilities have been consistently highlighted (Hornby 1995). Often good quality information and needs led training can help to combat some of the 'chronic vulnerability' (Carpenter 2000) which many parents of children and adults with profound and multiple learning difficulties experience. For as Randall and Parker (1999) state:

"The severity of the disorder at any level can leave parents exhausted to a degree that is dependent on their stress tolerance. Many of them experience chronic pessimism, and risk breakdowns in their functioning."

Designing appropriate training for parents is not as easy as it sounds. As Carmen Basil (1999) a speech and language therapist, points out, in the past professionals may have been guilty of trying to impose their skills on parents, rather than nurturing the skills that respond to their needs, and support them in the complex task of parenting a person with PMLD.

A parallel problem is that much training has focussed on the 'parents as partners' model. This is too narrow an interpretation. Our task should be about supporting families, who form the natural context for the child/adult with PMLD (Carpenter 2001). Brothers and sisters have worries and concerns; grandparents may have issues to resolve; and what of those non-blood relative family members, the 'significant others' comprising friends, neighbours, colleagues etc.

At Sunfield School, Worcestershire a Family Charter has been developed which opens with the words: "Sunfield welcomes all our children's families, friends and others significant in their lives."

One of the commitments made in this Family Charter, in a clearly stated spirit of 'working together', is training. For any family member, if the experience is to be of value, it has to be worthwhile, and this is underpinned by 'the tangibility factor.' Needs-led training is a very tangible experience that can have a positive impact on any family member, it enables them to know that services are there for them.

As English and Essex (2001) point out in their extensive family/carer survey based research, "Families are eager to engage in any training that will increase their ability to understand and support their children, but very few have access to this form of support."

Building upon the recent development of its Family Services, Sunfield School is organising a week of courses and training events for families of children/adults with disabilities in June 2002. This course will be called 'Celebrating Families' a deliberate antidote to the persistent negative image painted of the stresses and strains of rearing a child with disabilities. There are joys too!

The events will be hosted in the Sunfield Professional Development Centre, Clent, Worcestershire. They will be led by Don Meyer from the USA. The key event during the week will be the 'Celebrating Families' Conference. The week opens with a day of training on 'Sib Shops' a highly successful approach used for working with brothers and sisters of children with special needs (Meyer 1997).

Other days during the week are then only for various family members - mothers, fathers, grandparents and adult siblings. The Schedule is detailed below. So if you are a family member or know of families who would be interested in celebrating their familyhood, then please encourage them to come along and participate. They are unique; their concerns are unique; they are also to be celebrated as unique individuals - part of a family.

Nina Lewis
Sunfield School
Clent
Stourbridge DY9 9PB

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Celebrating Families

A week of family focussed events led by Don Meyer

Saturday 29th June 02	SUPPORTING SIBLINGS <i>A day for professionals</i>	A day for professionals to understand more of the needs of brothers/sisters, and how to support them by means of Sib Shops
Monday 1st July 02	FAMILY ISSUES <i>A day for grandparents, aunts, uncles and others</i>	This day would enable extended family members to explore and share, their insights as part of a family where one of its children has a disability
Tuesday 2nd July 02	CELEBRATING FAMILIES <i>A one day Conference for professionals working with families of children with disabilities</i>	This is a day for professionals who are working with, and supporting, families of children with disabilities/special educational needs. It will explore some of the key elements in delivering family focussed services
Wednesday 3rd July 02	MUMS THE WORD <i>A get together for mothers of children with disabilities</i>	This would be an opportunity for mothers to reflect on family life when one of those family members has a disability MUMS ONLY!
Friday 5th July 02	A LIFE LONG JOURNEY <i>A day for adult siblings of people with disabilities</i>	This event would bring together adult siblings of people with disabilities
Saturday 6th July 02	UNCOMMON FATHERS <i>A day for dads of children with disabilities</i>	This is a day for Dads only; a chance to talk about issues particular to them in their role as fathers of a disabled child

report back

SHERBORNE CELEBRATION DAY 15th September 2001

This day of celebration of the work Veronica Sherborne included the launch of the new edition of Veronica Sherborne's classic book *Developmental Movement for Children* and took place at the University of Birmingham on 15th September, 2001.

The day started with a movement session in the morning, led by George and Cyndi Hill which was much enjoyed by the participants. The formal celebration followed after lunch.

Bill Richards opened the proceedings and welcomed everyone, friends and colleagues from the UK, Belgium, Norway and Poland. Veronica's daughter, Sarah said how delighted she was that the book was back in print, and expressed her appreciation to all those who were involved and in particular Clive Langdon the photographer, Cyndi and George Hill, Andrea Wood of Worth Publishing, Janet Sparkes of St. Alfred's College, Winchester. Cyndi then thanked all those other people who had contributed in different ways.

Andrea spoke about the very positive experience that republication of the book had been and then officially launched the book when she handed over the first copy to Sarah. The toast was 'To Veronica and the continuation of her work'.

The second part of the afternoon looked at the past, present and future of developmental movement. A compilation of extracts from all six of the original videos was shown, and delegates from Belgium and Norway spoke about aspects of their work.

Alleyne Cliff, present chairperson of the Sherborne Association UK outlined the work of the association, and described a training package which she is developing with Ann Esbester and Peter Bruckenwell. Dr. Elizabeth Marsden spoke of the future in terms of research through liaison with the Universities.

Christopher Robertson of the University of Birmingham School of Education spoke about the Sherborne Archive which is now part of the main archive of the University. He reassured participants that the archive will be accessible, although procedures for accessing it will be formal which will ensure that the archive will have a less 'ragged future' than it might in, say, the education library. He stressed how important it was that people know where it is, and said that he intended to disseminate information about the archive through practitioner and practitioner research journals.

Veronica Sherborne and Practice - A Dynamic Legacy

Christopher commented that child development has been neglected in recent years, within educational policy and there is a task to be done - to ensure that such knowledge is shared and researched more fully.

He also identified inclusive education is as an important part of policy and practice, and illustrated the inclusive nature of developmental movement as he experienced it as a student of Veronica's at Bristol.

He identified a number of areas where further research is needed:

- To collate and collect work written already, from different contexts and for different purposes.
- To further theorise Veronica's eclectic approach and to explore the empirical ground for its value.
- Explore the possibility of a funded scholarship to work on developing the knowledge base and its practical implications.

He said "your own training and development work is a vital part of this, as is the existence of the Sherborne network nationally and internationally."

His final comment is an important positional one. He said "The idea of an archive can lead us to think of reifying Veronica's work. This is not my vision of what needs to be done. Veronica's legacy seems to me to be captivating, enchanting and humane. It is also, in some senses an elusive one because of its eclecticism and the way it was so embedded in practice and what we might call grounded theory. I very much hope that we might continue to take her legacy forward, to learn more through practice, research and theory. As Antonio Machado, Spanish playwright and poet put it:

*Traveller, there is no path
Paths are made by walking*

I hope that we can create these paths together and with children, young people and adults, to grow and to be, and most importantly to care for each other."

Footnote:

It is intended that Veronica's materials will be an active resource for anyone wishing to pursue an interest in developmental teaching with children or adults. Christopher Robertson, School of Education, University of Birmingham will provide further information about the archive materials and is happy to discuss any research and development interests you may have.

Contact him on - tel: 0121 414 4832 or e-mail: C.M.Robertson@bham.ac.uk

Enhancing Quality of Life:
a project to develop transitional programmes for people
with profound and complex learning difficulties

Notes from Newsletter 4: September 2001

This newsletter provides a set of interim reports written by staff working in the project's four case study sites.

Barnet College and Creative Connections -The Institute

Common Objectives with Creative Connections:

A comparison of the two approaches, arts therapy and Intensive Interaction, was the main focus during the Spring term with visits to each other's sessions, viewing videos of each other's work with lively discussion of methods (similarities, differences and complementary elements). Staff at Creative Connections collaborated to produce a description and explanation of the Arts Therapy approaches used there as they are drawn from several areas of therapeutic practice and applied in an educational context. This practice has not previously been fully documented. The established philosophy, principles and techniques of Intensive Interaction inform work done at Barnet College.

A physical access audit has been carried out at Barnet College to provide a specific route through the college for wheelchair users which will ensure ease of access. A centralised teaching area for students with learning difficulties is also planned which will reduce travel between classrooms and enable the college to house specialist equipment for student with profound and complex needs.

Collaboration between further, adult and continuing education colleges: work on creating an effective forum to enable greater collaboration is under way. Barnet College and Creative Connections managers are negotiating for both colleges to be included in a review of day provision for people with learning difficulties living in the borough of Barnet.

Objectives specific to Barnet College:

Assessment, recording and reporting systems: using and amending the system which was developed last winter, and changes made to ensure that documentation is more meaningful for students with PCLD.

Development of the curriculum: Following the merger of Barnet and Hendon Colleges the focus has been on provision for students with PCLD. Work continues on augmentative and alternative communication and closer ties have been established with the Community Team's Speech and Language Therapist.

Objectives specific to Creative Connections - The Institute

Staff development: pilot training for five support workers/enablers who come with students from residential/home settings. One aim of the training is to encourage and monitor transfer between CC sessions and life at home/in the community and the effect on quality of life. It is hoped that accreditation will be in place.

Development of multi-disciplinary practice and multi-agency work and user involvement: These strands run through all the work, and potential collaboration on joint training and Joint Investment Planning.

Springfield Oaklands College

The focus has been on all aspects of transition including transition routes into college, the support needed and effective transition routes from college into new provision. Information about taster, transition and link courses has been written highlighting guidelines and management. Pre entry assessments have been revised to provide as much information as possible to support the learner in the initial stages of transition. Case studies illustrate collaborative partnerships to support students moving on.

Transition portfolios have been developed which give information about what the student has done at college, how he or she likes to learn, what 'makes them laugh or groan' and what they would like to do after leaving college. The personal portfolio gives details of the most recent work with individual goals and short term targets.

Work on curriculum documentation, with a description of methods and ways of working to foster greater inclusion.

Embedding of inclusive technology into the curriculum has been more problematic. The focus has been on acquiring specialist knowledge needed to develop a broad based use of technology, to inform future resource requirements and find ways of funding specific equipment to enable full access to the curriculum.

Oldham Site

Recently staff in Training into Employment have been working with students with profound and complex learning difficulties and from this several themes have arisen:

Communication spanning a variety of levels is illustrated by case studies the first of which demonstrates how a member of staff who is not communication specialists has learnt to 'enter their world of communication as a starting point for beginning a relationship.' The second case study showed the importance of optimum communication between agencies to sustain individual ways of communication. It is suggested that a longer period of transition may be required to allow for training of staff in communication needs. A Communication Dictionary is being used throughout the service to address this issue. The compilation of the communication dictionary is carried out as a group activity which is recorded on video. The contribution of family is seen as crucial. The video 'has enabled us to capture expressions, movements and interpretations which would not be as meaningful on paper.' This information is disseminated to agencies involved with the individual.

The number of agencies involved in the transition of students and sustaining interagency approaches has also been a concern due to changes in practice or cuts in funding, which can lead to raising of hopes and aspirations which may not be fulfilled.

One student has completed a six week work experience at a local supermarket which has triggered a process of re-evaluation of preconceptions and predictions about opportunities which should be offered to individuals with profound and complex learning difficulties, and their responses to those opportunities.

Closing Comments

Project staff have started to analyse data and the preparation of the project outcomes which will include:

- a briefing paper highlighting the key issues for those involved in policy and planning at a strategic level;
- a guide for managers wanting to establish, sustain or develop provision;
- a pack to support staff development on a range of topics;
- a video;
- a review of the relevant literature;
- a set of Quality of Life indicators for evaluation and review at a range of levels.

The launch and dissemination of the project outcomes is being planned. An active dissemination will include the following:

- A ministerial launch in February 2002 to familiarise a wide audience with the outcomes and implications.
- Local networks for practitioners from a range of agencies who will share the dissemination in their own localities with a view to establishing on going networks for support and development.
- 20 plus supported implementation projects designed for organisations who want to develop their existing provision or establish new provision for these learners.

Further details will appear in the next Quality of Life project newsletter. *In the meantime if you are interested in co-ordinating, hosting or contributing to a local network or if you might like to be considered as a site for an implementation project we would like you to express an interest AS SOON AS POSSIBLE. Contact:*

Peggy Nunn, University of Cambridge, Faculty of Education, Shaftesbury Road, Cambridge, CB2 2BX. E-mail: plm20@cam.ac.uk

letters.....and.....e-mails

Some time ago I received this e-mail from Deana Davies, North Oxfordshire College, Broughton Road, Banbury, Oxon OX16 9QA

Tel: 01869 346850

e-mail: deannadavies@deannadavies.screaming.net

We are trying to set up a PMLD FE Unit in North Oxon (which has no post 16 provision in schools). I am setting up a centre for 4/5 students experiencing PMLD and am having difficulty in finding a suitable curriculum. I am also struggling to find specialised educational equipment. I do have a few catalogues but don't want to buy unnecessary equipment.

I would be grateful if you could point me in the right direction.

Many thanks

Deanna Davies

Those readers who are known to be involved in FE work contacted immediately, but if you work in FE or with this age group, I am sure that Deana would be very glad to hear from you. There is very little published about FE which is a vital transition period from school to the adult world and services, and a fascinating area for debate.

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

REPORT HIGHLIGHTS SHOCKING LACK OF SUPPORT FOR PROFOUNDLY DISABLED PEOPLE AND THEIR PARENTS

Press release following the launch of the Mencap report *No Ordinary Life*
at the Valuing People - Voices Unheard conference held in London in November 2001

Social Services must end the exploitation of parents of people with profound and multiple disabilities who receive little or no help with their huge lifelong caring role, according to a report *No Ordinary Life*. Researchers found that parents who look after their sons and daughters at home were regularly devoting over 18 hours a day to care but in contrast were receiving only 20 minutes a day of outside help.

People with profound and multiple learning disabilities are deeply loved and valued by their parents but caring for their offspring has left families permanently exhausted, financially disadvantaged and isolated from society. The needs of people with profound and multiple disabilities are far greater than for most elderly people or young children - they simply cannot live without the help of others. They need round-the-clock support with every aspect of their lives such as eating, drinking, washing and managing incontinence and many need to use life-saving technology such as oxygen cylinders, suction equipment or tube feeding.

But despite these high support needs they and their families are not classified as needing critical help, leaving parents unsupported and taken for granted. Mencap is urging the government and social services to overhaul the help available to parents, particularly in the light of evidence that the number of children and adults with profound and multiple learning disabilities is increasing every year.

Fred Heddell, Mencap's Chief Executive, said: "Our report shows the shocking lack of support that parents get with looking after their son or daughter. They love their children and want to do everything possible to give them a good quality of life. They spend most of their waking hours caring for them, and are often woken at night, but get virtually no help. They are at the bottom of the list for services and we urge Social Services to stop exploiting these parents and provide them with the help they deserve."

Sharon Beverley-Hughes, from Colwyn Bay in North Wales, whose 15-year old son has profound and multiple learning disabilities, said: "No matter what we say as parents, until you actually have a child with special needs, and you have no book to follow, and that child needs your attention 24 hours a day, 365 days of the year, then you will never know how hard, how dedicated and how much you learn from each other and how much love you receive from this child, because you give love unconditionally."

Mencap conducted 76 in-depth interviews with parents of children and adults with profound and multiple learning disabilities. The *No Ordinary Life* report found that:

- 60% of parents spend more than 18 hours a day caring for their sons and daughters - over 120 hours a week;
- 78% of parents receive either no support or less than 2 hours per week to help them cope at home with their caring needs. This is on average less than 20 minutes per day and is in stark contrast to the 18 hours or more per day spent on caring;
- The average number of times parents were woken up at night was three. When parents were woken at night they invariably had to spend time changing or bathing their son or daughter due to incontinence, leading to their having very little sleep;
- 48% of people received no support from outside the family to help with their care tasks.
- 66% of families did not believe that the financial support they received covered their extra costs incurred as a result of their son or daughter's disability.

Mencap's report recommends that:

The government should ensure that Social Services regard those with profound and multiple learning disabilities living at home as a critical priority group and target their services towards them. Social Services and Local Learning Disability Partnership Boards should identify the number of people with profound and multiple disabilities in their area, review the number of households currently receiving domiciliary care, both during the day and at night, and review and improve services for all parents and carers

For a copy of the *No Ordinary Life* report, contact Mencap's Public Liaison Unit on 020 7696 6900 or www.mencap.org.uk

David Fulton Publishers acquired by Granada Learning

In September, David Fulton Publishers was acquired by Granada Learning - a group of companies which are "the leading force in UK Education, with a wide portfolio of expertise in all key areas." This includes software, video, textbook publishing, special educational needs publishing, training, testing and assessment, and online learning.

This move will ensure a secure future for David Fulton Publishers, its authors and staff. David is confident "that all the special qualities of Fulton Publishers - our attention to authors, speed of production, commitment to ITT and special needs - will continue to flourish under the new arrangements."

It is business as usual for everyone with David Hill continuing as managing director and David Fulton continuing as director of publishing.

New Learning Disability Helpline

On 4th December the Health Minister Jacqui Smith launched the new Learning Disability Helpline at the headquarters of Mencap. This is the first national Learning Disability Helpline in England and it has been set up with a three-year grant from the Department of Health with match-funding from Mencap.

The helpline, which will be run by Mencap, will provide a much-needed 'one stop shop' information and advice service on a wide range of issues including support, welfare benefits, health, housing, learning and employment for people with learning disabilities, parents, carers and social care professionals.

Contacts for Mencap: Kate Gould - 020 7696 5594/Helen Ketton - 020 7696 6937

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

Baseline Assessment, Curriculum and Target Setting for Pupils with Profound and Multiple Learning Difficulties

Written by Sonia Maskell and Fran Watkins with Elizabeth Haworth: Edited by Erica Brown.

Published by David Fulton Publishers 2001

This book sets out the approach to the curriculum and planning, assessment, recording and reporting developed by the authors at an independent special school for pupils with profound and multiple learning difficulties. It provides an interesting description of the Baseline Assessment and Target Setting Scheme (BATS) developed by them and its uses.

The authors' focus is upon pupils with profound learning difficulties who also have a physical disability and possibly sensory impairments or additional medical difficulties. They state clearly some fundamental principles that underpin their work and sketch out the development of the school curriculum and BATS as their response to government initiatives. Readers will be pleased by their emphasis on the holistic development of the individual child and their statements about the importance of a responsive environment, the need for collaboration with parents and other agencies and the value of detailed assessments in formulating appropriate skill-based learning objectives and relevant plans.

It is always intriguing to see how schools have developed their own approach to planning, assessment, recording and reporting. The descriptions of their version of an Individual Education Plan (IEP) and individual learning programmes (ILP) are probably of great use to teachers who are relatively new to this field of special education. Regrettably, there are only a few case study examples of completed plans and records; additional examples would have been far more informative than the many blank versions included, especially when it comes to important areas like moving and handling assessments, eating and drinking programmes and feeding programmes.

The ILPs set out a few skill-based learning objectives, most frequently connected with communication and use of information and communication technology, and these are delivered on a daily basis in intensive, but short, one-to-one sessions. There is little detail about teaching methods other than brief reference to intensive interaction, responsive environments and small-steps skill based teaching and only a few references to practical texts. A wider range of experiences, related to the National Curriculum subjects, is delivered through planned group sessions that allow functional communication skills to be generalised once they have been learned through ILPs. Clearly, the development of appropriate activities is still ongoing in relation to the Foundation Subjects of the National Curriculum. Again, I would have welcomed some completed examples instead of the blank versions of pupil record sheets and 'records of achievement and experience' which they have developed for English, mathematics and science.

Through no fault of the authors, the publication of this book actually precedes the recently produced DfEs/QCA curriculum guidance for teachers of pupils with learning difficulties that has much relevance. Also there is no detail about the possible uses of BATS in the process of whole school target setting, although they recognise this as a major issue facing practitioners working with these pupils.

The book probably contains little for experienced specialist teachers, although it should be helpful for others with less experience of this group of pupils. It is a short book, (70 plus A4 pages and probably less than 15,000 words) and it is an easy book to read. More schools should publish their curriculum documents and these authors certainly deserve praise for doing so. As a result, this is a book that ought to be in the professional library of every special school that caters for these pupils.

*Rob Ashdown
Headteacher, St. Luke's School
Scunthorpe*

Better Choices - Fuller Lives: Working with People with Profound and Complex Support Needs. Managers' Reader.

By James Hogg & Loretto Lambe. First Draft Publications, BILD Kidderminster. 2000

This excellent book is a must for all home managers, but the book would also be beneficial to all who are involved with people who have profound and complex support needs.

The book consists of 6 main parts which are namely:- services, staff and service users; the effects of disability on living and learning; building relationships; learning for everyday living; learning in the wider world; developing and managing high quality services.

The reading is extremely interesting and presents a good equal balance of differing theories and views. Occasionally it felt as if the authors were toying with the reader, leading the reader down one particular familiar path, then suddenly as the paragraph closes the reader is left at a different place. This method of presentation made the reading all the more interesting and informative. It felt as if there was a higher interactive element happening between the reader, the written text and the authors.

Following each of the main parts there are some well thought out and planned activities to complete. The activities help to translate the reading into everyday practice, since most exercises are about assessing and reflecting on relationships, practices and the environment of the readers' working environment. Some of the activities also ask the reader to consider ways forward. Whilst others call for the reader to update themselves and help to clarify a manager's perception of the service he/she manages.

However the last part differs from the previous parts in that the authors offer 6 critical factors that have to be achieved in order to say that the service is effective and a successful quality service. Measurements, performance indicators and actual performance statements are given in a matrix to support each critical factor. Each performance indicator is then further discussed with the measure outlined for achievement. The reader can complete these working on his or her own service. The book takes the reader through each stage. This

last part really pulls together the main strands of the earlier parts of the book.

The only down side of this book is the over complicated system of terminology relating to parts, units, MRPs and sections. Having read the book I am still unclear as to how the differences are defined and why they are all necessary. However I would advise would be readers not to spend too much time over this issue, or you'll lose the threads of the excellent text.

*Diana M Foxwell
Lecturer Faculty of Health and Social Care
UWE /Distance Tutor School of Education,
University of Birmingham*

NEW BOOKS AND RESOURCES

Baseline Assessment, Curriculum and Target Setting for pupils with Profound and Multiple Learning Difficulties by Sonia Maskell and Fran Watkins with Elizabeth Haworth, edited by Erica Brown. Published by David Fulton Publishers 2001. This book is reviewed in this issue.

Developmental Movement for Children: Mainstream, special needs and pre-school (2nd Edition) by Veronica Sherborne with preface by Sarah Sherborne and Foreword by Janet Sparkes for the Sherborne Association. Published by Worth Publishing 2001.

Better Choices - Fuller Lives: Managers' Reader by James Hogg and Loretto Lambe, published by BILD Publications 2001. A companion book to the Independent Study Units for staff working with people with profound learning disability. This book is reviewed in this issue.

The Team Around the Child by Peter Limbrick, published by Interconnections 2001.

Readers of the last issue will remember the article written by Peter which aroused a great deal of interest.

Good Practice in Citizen Advocacy by John Brooke, published by BILD Publications 2001. Guidelines to citizen advocacy groups and good practice in areas such as basic principles, individual rights and advocacy partnerships.

Telling it How it is by Carrie Britton, published by Handsel Trust 2001

Research into the family's perspective: what it is really like for families managing their child's serious condition at home.

The Keyworker: a practical guide by Gudrun Limbrick-Spencer, published by Word Works 2001

Practical information about how to provide a keyworker service including suggestions for adopting the principles behind keyworker support in other schemes.

No Ordinary Life: the support needs of families caring for children and adults with profound and multiple learning disabilities produced and published by Mencap 2001. The Report aims to draw attention to the rise in the number of children and adults with profound disabilities and improve understanding of their needs, and the needs of their parents and families.

Leaving Home, Moving On a booklet produced by the Foundation for People with Learning Disabilities which introduces housing options for parents and carers of people with learning disabilities. Available from the Foundation Tel: 020 7535 7420.

Get Moving! A new booklet written by the Norah Fry Research Centre and produced by the Foundation for People with Learning Disabilities to help people with learning disabilities make their own decisions about where to live. Available from the Foundation Tel: 020 7535 4200.

The Art of Partnership: A Practical Guide written by Anita Cameron published by BILD Publications. This guide is for anyone in learning disability services about to embark on joint working, or looking for ways to improve their current practices.

Easy Guide to the Human Rights Act 1998 by Andrea Hughes and Phil Coombs, published by BILD Publications. A guide for staff, carers and parents which outlines the key elements of the Act and shows how they can be applied to protect the legal rights of people with learning disabilities.

Sight Matters - a video about eye tests produced by RNIB available with or without British Sign Language. Contact RNIB Customer Services - 0845 702 3153

COURSES AND CONFERENCES

JANUARY

23rd

Access 1

An introductory day Tate Britain for careworkers and support staff on how the gallery can be used as a resource and adapted to the needs of a range of client groups. This course is free.

Organised by: Tate Britain Community and Access Programme
Venue: Tate Britain
Further details: Tate Ticketing
Tel: 020 7887 8888

30th

Listening to Families. Talking to Families

This course explores the issues surrounding the needs of families of children with severe learning difficulties and how these may affect the way in which we work with families. The importance of developing systems and practices, which promote positive communication and address the needs of the whole family.

Organised by: Sunfield Professional Development Centre
Led by: Prof. Barry Carpenter, Principal and CE, Sunfield
Sally Conway, Co-ordinator of Family Services, Sunfield
Venue: Sunfield Professional Development Centre
Further details: Sunfield School
Clent, Stourbridge DY9 9PB
Tel: 01562 883183

FEBRUARY

1st

Sherborne Movement Level 1

Overall view of Sherborne Developmental Movement. The focus will be on practical activities which illustrate two main objectives of Sherborne's work - developing 'awareness of self' and awareness of others' through movement activities.

Organised by: Sunfield Professional Development Centre
Sherborne Foundation
Led by: Cyndi Hill, Sherborne Foundation
Venue: Sunfield Professional Development Centre
Further details: Sunfield School
Clent, Stourbridge DY9 9PB
Tel: 01562 883183

5th
and
6th

Cultural Issues in Sexuality Work with People with Learning Disabilities

This course will explore different cultural attitudes towards sex education and people with learning difficulties within services, as well as the practical implications of carrying out sexuality work with service users from a range of cultural backgrounds within an equal opportunities framework.

Organised by: CONSENT
Led by: Seema Malhotra
Venue: Harperbury, Herts or Brent
Further details: CONSENT
Tel: 01923 670793
e-mail: consent@hnhsrc.demon.co.uk

6th

Life Story Work

This course is for anyone working with people with learning disabilities who would like to explore the benefits and practicalities of the use of life stories with the people they work with.

Organised by: BILD
Led by: Linda Mawson
Venue: London
Further details: Liz Howells, BILD
Tel: 01562 850251
e-mail: lizh@bild-edn.demon.co.uk

6th Engaging with art through movement
 A new course for pairs of support staff and clients with learning difficulties to explore how they can use movement activities as a strategy for exploring art works. We will also look at how art works can inspire movement and dance work in other settings. Staff should have attended Access 1 (23rd January)
 Organised by: Tate Britain Community and Access Programme
 Venue: Tate Britain, London
 Further details: Tate Ticketing
 Tel: 020 7887 8888

19th Numeracy for very special pupils
 The course covers the development of fundamental mathematical concepts and skills that later learning depends upon. It relates this fundamental learning to the lives and needs of children with very special needs. All is related to the National Curriculum and the Numeracy Strategy, and the whole course is illustrated by the use of resources that bring life, wonder and humour to mathematics in the classroom.
 Organised by: Sunfield Professional Development Centre
 Led by: Les Staves, independent educational consultant
 Venue: Sunfield Professional Development Centre
 Further details: Sunfield School
 Clent, Stourbridge DY9 9PB
 Tel: 01562 883183

26th Citizenship for pupils with learning difficulties
 This course explores the subject of citizenship and its relationship with PSHE for pupils with learning difficulties; practical implications within the Curriculum; strategies for teaching and assessing citizenship; practical ideas for the classroom.
 Organised by: Sunfield Professional Development Centre
 Led by: Hazel Lawson, Senior Lecturer in Education
 Venue: Sunfield Professional Development Centre
 Further details: Sunfield School
 Clent, Stourbridge DY9 9PB
 Tel: 01562 883183

27th Access 2
 A follow-up course for careworkers and support staff to develop skills in using art works with clients - planning a gallery session, questioning and devising appropriate activities.
 Organised by: Tate Britain Community and Access Programme
 Venue: Tate Britain, London
 Further details: Tate Ticketing
 Tel: 020 7887 8888

MARCH

1st Key Skills across the Key Stage
 This course will explore the role of the key skills and other priority areas of learning in the light of guidance from QCA, DfES and the Basic Skills Agency. The issues addressed will be relevant to practitioners and policy makers working with young people with learning difficulties in school and in their transition to adult life.
 Organised by: Sunfield Professional Development Centre
 Led by: Richard Byers, Lecturer in special and inclusive education
 Venue: Sunfield Professional Development Centre
 Further details: Sunfield School
 Clent, Stourbridge DY9 9PB
 Tel: 01562 883183

5th Teamwork in Early Intervention for children with complex needs
 A conference for support workers and parents.
 Organised by: Handsel Trust
 Venue: City Hospital, Birmingham
 Further details: The Handsel Trust
 Tel: 0161 740 7757
 e-mail: p.linbrick@u.genie.co.uk

9th and 16th Access 3 Supporting Independent Visits
A two part course for staff working with adults with learning difficulties which introduces handling objects and learning resources that can be borrowed to support independent gallery visits. Part 1 is for staff only, Part 2 for staff/client pairs.
Organised by: Tate Britain Community and Access Programme
Venue: Tate Britain, London
Further details: Tate Ticketing
Tel: 020 7887 8888

15th Children with Complex Healthcare Needs: Supporting Child and Family at Home and School
Conference chaired by Dr. Philippa Russell, and Professor Patricia Sloper
Organised by: Handsel Trust
Venue: Derby
Further details: Peter Limbrick, Handsel Trust
Tel: 0161 740 7757
e-mail: p.limbrick@u.genie.co.uk

MAY

14th Sexuality and Personal Relationships
An introductory course aimed at anyone wishing to develop awareness and understanding of sexuality in people who have learning disabilities.
Organised by: BILD
Led by: Paul Eggett
Venue: Birmingham
Further details: Liz Howells, BILD
Tel: 01562 850251
e-mail: lizh@bild-edn.demon.co.uk

14th to NAIDEX 2002 Exhibition
Healthcare and rehabilitation equipment, conference and seminar programme.
Organised by: Touchstone Exhibitions and Conferences Ltd.
Venue: National Exhibition Centre, Birmingham
Further details: Maria Lenaghan, Touchstone
Tel: 020 8332 0044
e-mail: naidex@touch-stone.co.uk

JUNE

29th A Week of Celebrating Families
A week of day courses for Siblings, Grandparents, Mums, Dads plus a 1-day Conference for Professionals. (See article in this issue)
Organised by: Sunfield Professional Development Centre
Venue: Sunfield Professional Development Centre
Further details: Sunfield School
Clent, Stourbridge DY9 9PB
Tel: 01562 883183

18th Communication through Drama
A course for anyone working with people with learning disabilities who would like to explore the benefits and practical use of drama in working alongside people with learning disabilities in creative and fun ways to encourage self-expression.
Organised by: BILD
Led by: Linda Mawson
Venue: Birmingham
Further details: Liz Howells, BILD
Tel: 01562 850251
e-mail: lizh@bild-edn.demon.co.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.

Monday 14th January

Tuesday 22nd January

Wednesday 6th February

Thursday 21st February

Friday 8th March

Saturday 23rd March

Monday 8th April

Tuesday 23rd April

Wednesday 1st May

Thursday 16th May

Friday 7th June

Saturday 22nd June

Monday 1st July

Tuesday 23rd July

Booking form from:

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

Tel: 01926 650195

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 Tel: 0121 678 2353

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: Certificate, Advanced Diploma and Masters.

University of Manchester Faculty of Education

Further details: The Programme Secretary, Educational Support & Inclusion,

JT1 Office, University of Manchester, Oxford Road, Manchester M13 9PL

Tel. 0161 275 3337

e-mail: JT1Office@man.ac.uk

Certificate in Working with People who have Learning Disabilities

New distance learning courses from BILD for staff working in the learning disabilities field.

All courses are accredited through the National Open College Network and allow students to study in their own work place, using quality materials with support from friendly and professional tutors.

The following three courses start in February 2002.

Better Health

Ageing Matters

Better Choices for People with Profound and Complex Needs

The following single units are also available to start at any time:

Induction to learning disability services

Foundation: communication

Foundation: abuse

Further details: BILD Learning Services

Tel. 01562 850251