

PMILD LINK

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

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

As always in spring change is in the air, although like the weather this year, spring seems to have slipped by unnoticed and we are now into summer. You may have - a new volume with three issues in each subscription year. The advantage (we hope) is that you should know how many you have had for your current subscription - and also whether it is time to resubscribe!

You may wonder whether the number this time is a misprint, but we decided to use the number which we would have reached if we had been using this system from the beginning. Unbelievably, PMLD-Link has been going for eleven years, as you can see. It has changed quite a lot since the first beginnings, but I hope has not lost the emphasis on practical support offered by people who are actually 'doing the job' whether they are parents, carers or professionals.

Another change is an increase in the number of people on the editorial group. This will mean that more people will be at each editorial meeting, giving more ideas and support. We have tried to get a better balance between those involved in children's services and those involved with adults, and also to have members based in different parts of the country so that the network of contacts is country wide. Our new members are: Helen Sanderson (North West), Steve Morris (South West), Jim Wolger (London and South East), Rob Ashdown (North East), John Lawton (Midlands) Steve Simmons (Midlands). We are very pleased to have a parent and a representative from Mencap among them.

Subscribers in Ireland will be interested to know that we now have a co-ordinator in Dublin who will collect all subscriptions and send one payment for all of them, thereby avoiding the excessively high charges for the transfer into sterling. Rosaleen O'Halloran of St. Mary's Hospital and Residential School suggested this to us, and has agreed to be our first co-ordinator. The next subscription year will be a trial run, and we hope very much that it will be a success, that it will not be too much work for Rosaleen, but will make PMLD-Link even more worth while for our Irish readers. You can contact Rosaleen at:

St. Mary's Hospital and Residential School, Baldoyle, Dublin 13 .Tel: 832 3056.

The topic for our next issue is Inclusion, and we are very grateful to Jean Ware for introducing this in Future Focus. So many people are involved in supporting inclusion in some form - some of it very successful, some of it less so. Do write and tell us about it - any highlights, or tips you can pass on.

BUSINESS MATTERS

Subscriptions

This is the second issue of the subscription year 1998/99 as you can see from the number! The next issue will include the subscription form for 1999/2000 when everyone should resubscribe for the Millennium Volume!

Articles

Articles or any other material for the next issue should reach me by the 6th September. They can be sent through the post or by e-mail. I am looking forward to getting them!

Carol Ouvry (editor)

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"I mean really, can you imagine?"

Communication as advocacy for students with complex needs

My position as Communication Support Worker at Sunfield residential school takes many different roles. My main aim is to advise staff how to improve their communication skills and how to improve the skills of the students by using Alternative and Augmentative Communication (AAC) systems. This, I hope, will improve the quality of the lives of our students who have Complex, Severe, and Profound Learning Difficulties.

A prime concern is working with our pre-verbal students. These students are of the ones that present the most challenging behaviour. The staff have a commitment to the student's autonomy and self advocacy and I see daily the ways in which the staff show respect for each student and how they help to promote the feeling of self worth for that student. An ongoing challenge is how we encourage our students to take control of their own lives. During training sessions I often use the following text, (this to me is the essence of many pre-verbal students' lives). It was written by a young lady named Sara Brothers (1991) who in later life found the means to express herself.

I know what its like to be fed potatoes all my life. After all, potatoes are a good basic food for everyday, easy to fix in many different ways. I hate potatoes! but then, who would know that only me? I know what its like to be dressed in red and blues when my favourite colours are mint greens and lemon yellows, and pinks. I mean really, can you imagine?

I mean really, can you imagine? I am sure everyone reading this article can imagine this. It is so necessary for the students to learn to make choices for themselves. These are the very first steps towards independence and the realisation that they can have an effect on the outcome of their own lives.

When a student has difficulty in talking and understanding what is said, it is hard to 'see' their active mind and it may seem difficult to envisage that the student has the capacity to make decisions for him/herself. This point is echoed by Wilkinson (1994) a teacher of students with PMLD who states that very often students are accused of being poor participants, when all too often they have no reason to participate as everything is done for them. I agree with Wilkinson and I am of the opinion that it is often easier to give the students what you think they might want rather than give them a choice. This creates a cycle of dominance by the staff/carer and compliance by the student, without the learner every displaying their full potential.

To communicate is not only about the ability to speak; when speech is delayed we need to find and use other suitable alternative communication aids. Furthermore we need to build upon any speech, gestures, signs, vocalisation the student may use. Carpenter (1997) writes that it really does not matter how the child/person communicates, just so long as he/she attempts to communicate. We must therefore interpret the individual's requests and build upon the various ways he/she conveys a message. Our teaching style must be interpretative rather than directive and so the power is given to the learner during the interaction.

At Sunfield we try to use whatever is appropriate to our students' needs and every communication aid is tailor made just for that special person. This may mean that we use several low-tech multi-modal approaches, such as objects of reference, symbols, photographs or pictures. This is always accompanied by the visual language medium of sign. If we appreciate that a significant proportion of our experiences are assimilated through our senses, especially sight and touch, then to offer visual and tactile

communication clues are of crucial importance to the education of people with profound learning difficulties.

In promoting self advocacy let us begin with giving the learner a 'voice'. We should encourage the use of an AAC aid; this can be done in many ways and almost everywhere in Sunfield displays a graphic symbol. This is to give the learner another clue. For example, we use symbols or photographs on cupboard doors. This shows the learner what is in the cupboard, and also acts as a constant reminder for them and hopefully, in time will reduce reliance on staff/carer.

We often begin a communication advocacy programme with the use of a simple choice board for food of fun activities using objects of reference, photographs or symbols. The choice board must be meaningful and motivating if we are to encourage communication. My advice to the staff is simple, when we begin the programme whatever we put on the choice board must be attainable for the student. Furthermore, if that person troubles to 'ask' for something, even if it is in the middle of the night, it should be given immediately and we should celebrate the achievement or the moment is lost. The acquisition of these skills is inevitably a lengthy process and every AAC aid is only as good as the person implementing it. Much support has to be given to the student whilst he/she learns to use it. If the aid is not used regularly and consistently there is little point to the exercise, and the aid becomes just a worthless gesture. Students with profound learning difficulties have a short memory and need constant repetition.

An example of the effectiveness of this augmented communication approach to advocacy is one of our young men who now chooses to drink tea in an afternoon, after years of being given squash because no one knew he liked tea. This same young man also makes a choice between cake or yoghurt for pudding by tapping a symbol. Small steps maybe, but important ones in providing a way to develop his autonomy.

Another young man now has a selection of photographs on a board which are kept near his table in the dining room. He can now 'ask' for things by pointing to the photographs. He 'asks' for ketchup, bread and butter, and cheese. This is a long way from when he used to push over the table when he wanted something. He also makes a choice of drinks; sometimes he chooses hot chocolate, sometimes squash, the choice is always his own. He has learned that he has a choice. He has been given the control and who knows where this may lead.

So many students with PMLD are capable of achieving so much more independence if we find the right communication channel for them. We are charged with helping them to develop these skills and give them confidence to speak for themselves.

Advocacy is for all - Can you imagine?

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February 1999

References

Brothers, S. (1991) in D.R. Beukelman and P. Mirenda. (1992) *Augmentative and Alternative Communication*. London/Baltimore: Paul Brookes Publishing Co. (p.5)

Carpenter B. (1997) in C.Latham and A.Miles *Assessing Communication* London: Fulton

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SUPPORTING A STUDENT WITH PMLD IN MAINSTREAM SCHOOL

According to the dictionary, advocacy is 'active support, especially of a cause'. It may also be important to remember that it can also be described as 'backing', or 'spokesman ship'. Advocacy is a subject which is discussed by many who come from different perspectives and have had different experiences of PMLD. There are those who provide backing and support, who enable those with disabilities to have their voice heard; and those who act as spokespeople for those with PMLD. When discussing such an issue it is important to remember that it is not merely about providing services and is certainly not about making decisions for others, but more importantly is concerned with providing choices and enabling those with PMLD to become more empowered and to get the most out of life.

Having finished university a year ago, where I studied Education and in particular special needs, I have a grounding in the theory behind the subject. My only experience prior to this year was the placement I held in a special school. To me, this was for many the only option, where staffing was short and the children didn't always get the time and support they needed and deserved. Due to lack of experience this was my considered opinion despite having been told repeatedly by lecturers that almost any child can and should be included in mainstream education. I have to say, however, that through the privilege of supporting Claire, my views have altered somewhat. I cannot claim to be an expert on the subject, but each day I am with Claire I become more convinced of the importance of advocacy and that inclusion is the way forward. Claire is my teacher, and in her own way lets me know what she wants.

It may be useful to provide a brief outline of Claire's experiences in order to understand a little more of why I feel as I do about advocacy. Claire has PMLD and began her formal education in the special sector, where her parents could see that she was not happy and perhaps even being held back in her development by the system. As a result of their loving support and battles with the authorities on Claire's behalf, she has now been in mainstream education for nine years. Throughout her life Claire has put up with professionals doing what they say is best for Claire. Many have stepped into her life for a brief period and informed those who really love and support her that they and they alone know what is best for her. Unfortunately this is all too common. If Claire is to be empowered, she needs to be given her own voice. In her own way, she communicates very clearly if only more people would stop and learn to listen.

I have only been supporting Claire since she has been at the local mainstream sixth form college. It has its ups and downs, but on the whole we enjoy it. Claire, just like any teenager dislikes having to get out of bed in the morning to go to college and doesn't always want to be in lessons, but she needs her friends about her in daily life as we all do. Claire has formed many special friendships at college. Some of these friends she has known since primary school and others she has only met this academic year, but all of them are there to support her, to share lunch with her and to have a laugh with her. When you spend time with Claire it really is apparent just how important mixing with your peer group is. A simple hello or smile makes all the difference.

At college Claire is given choices just like everyone else. As she is over sixteen she no longer has to follow the National Curriculum and so can go to those classes which she enjoys. It is also, in part, about trial and error. We may attend one

subject a few times before we realise that it isn't suitable, for whatever reason. Claire also lets us know quite clearly when she's had enough. In many ways flexibility is the key. Claire is entitled to change her mind about what she wants to do, situations also change. What may work once, may never work again. Putting work aside, being at college is a great opportunity to socialise. With over a thousand students there are plenty of opportunities for a chat. Claire must have the right to be with her peers and being at college allows her to do that. It is great to see her as stimulated as she is when at college. She gets bored and frustrated so much more easily when she doesn't have people around and isn't involved with the hectic life of being at college.

My experience of advocacy is a positive one on the whole. Although there are those involved in the field who perhaps make it more difficult than it need be. As I mentioned before, I am by no means an authority on the subject, but Claire is my teacher and she teaches me how to support her best - how to become empowered. It is vitally important that as people involved with advocacy we take time to stop and really listen rather than merely continue in the fight for gaining 'their rights'. We should be supporting them in gaining their *own* rights. This is nicely expressed by Jenny Corbett who wrote:

"We can listen but not hear. It is only when these new voices are given value within the disability special needs discourses that they will become more widely heard." (Corbett, 1996 p.69)

With the right attitude and help, those with PMLD can live their lives to the full:

**"If
you believe in me
then maybe
I can do something worthwhile
maybe I can do something with my life
thus
the light of hope begins to burn
your constant trust in me
communicates a warm sensation of confidence
and faith
that look in your eyes
the touch of your hand
brings me some marvellous message of hope.
(Vanier, 1991 p.33)**

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References

Corbett, J. (1996) *Bad Mouthing*. London: Falmer Press

Vanier, J. (1991) *Tears of Silence*. London: Darton, Longman & Todd

CITIZEN ADVOCACY FOR PEOPLE WITH PROFOUND AND MULTIPLE LEARNING DIFFICULTIES

If anyone can benefit from having a citizen advocate, it is the person with PMLD. The two are natural partners.

Citizen advocacy is all about partnership between two people, one at risk of being unheard by others, and another willing and able to be that person's voice. Advocacy is not solely for people with learning difficulties. The elderly, and those suffering from dementia or from head trauma, are among many others who can benefit. But the nature of citizen advocacy gives it a particular value to those with PMLD who cannot effectively access group or self-advocacy.

A citizen advocate is an ordinary person: an unpaid volunteer, independent of services such as health and social care, and of families and other carers, who is prepared to establish communication with someone who finds it difficult to express an opinion, or to have it listened to. The role of the advocate is, so far as they can be determined, to speak up for the wishes, views, and preferences of an advocacy partner who cannot do so in person. This demands a one-to-one commitment on the basis not only of objectivity, but of trust and confidence.

To achieve this takes time. It is not uncommon for the first six months or more of an advocacy partnership to be spent in establishing basic communication and a sense of trust. Two years or longer may be needed to get the partnership fully up and running. Even then, no citizen advocate can be completely certain of understanding what a partner with PMLD is trying to communicate in terms of choices and decisions.

Often in such circumstances, the advocate must speak up in what appear to be the partner's best interests, based on a good knowledge of the person. It is here that the qualities of the ordinary citizen are of such value: a sense of right and wrong; an urge to see fair play; an understanding of what it is like to be in someone else's shoes; and common sense.

Yet there is more than personal attributes and communication skills to being a citizen advocate for someone with PMLD. Such an advocacy partner will need a great deal of support to make choices and decisions, or even to understand that the possibility of effective choosing exists. There are also issues of their particular vulnerability, and need for protection from harm. Citizen advocates who partner people with PMLD need sound preparation in developing good disability awareness.

Having said this, the underlying principle of citizen advocacy is the same for all. The advocate speaks for the partner, and for the partner alone, uninfluenced by either personal opinions, or those of others. This is the heart of citizen advocacy.

It sounds wonderful, and it can be. Probably, everyone reading this knows someone whose life could take on new meaning through a citizen advocate. So, how to find one?

This is where the snags begin. In this country, citizen advocacy is like a patchwork quilt on which a good start has been made, but which is far from finished. There is no one citizen advocacy movement. The many existing advocacy groups do not all network together, and, if they did, would not cover every area. It can be difficult to set groups up, and some come and go as funding and volunteers are found, or dry up. Again, if there is a local group, there may well be a waiting list. The demand for advocates is always greater than the supply.

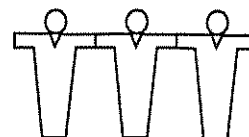
Behind this situation are to be found issues of the standing and funding of citizen advocacy. Unlike many parts of the world, here the citizen advocate has no legal status. Equally, there is no secure and independent financial support for advocacy groups. Most depend on the goodwill of health authorities and social services, increasingly on lottery funds, and on the occasional legacy or other windfall.

Such issues were in part addressed by Sections 1 and 2 of the Disabled Persons (Services, Consultation and Representation) Act 1986 – yes, that long ago – which established a legal framework for advocacy and placed an obligation on local authorities to develop services. These were never brought into effect, apparently because of the cost implications. But they may not be entirely lost. *Building Expectations*, the 1996 Report of the Mental Health Foundation Committee of Inquiry, recommended that the Government should implement both. Their ghosts have been raised this year in a follow-up by the Lord Chancellor's Department to the 1997 consultation paper, *Who Decides?* Something may just possibly be afoot.

Citizen advocacy is at a crossroads. Growing attention is being given to how, and in which direction, to move the concept forward. This can only be to the good, provided the debate focuses on serving the interests of people, especially those with PMLD, whose voices are not being heard in decision making about their own lives.

The Third Party Advocacy Project of the British Institute of Learning Disabilities is funded by the Foundation for People with Learning Disabilities, as part of its Choice Initiative, and by the Home Farm Trust. Its remit is to develop resource materials to be used in the training of citizen advocates who will partner people with severe, profound, and multiple learning disabilities. The resource pack is currently undergoing pilot trials with advocacy groups, and is planned for publication in early 2000.

John Brooke
Project Officer – BILD Third Party Advocacy Project
Wolverhampton Road, Kidderminster, DY10 3PP.



The Sense Advocacy Network aims to provide a forum to share skills, experience and ideas around advocacy for people with sensory impairments and multiple disabilities. We provide training, information, advice, and consultancy. Anyone who has an interest in advocacy for people with sensory impairments and multiple disabilities is welcome to join the network; membership is free. We have over 230 members who range from advocacy organisations to social services departments; individuals and families to health services.

We provide members with regular newsletters and provide information and advice on issues surrounding advocacy. Requests for information and advice range from help in identifying advocates to information on how to support advocates with a sensory impairment. We can answer inquiries on issues ranging from setting up a new advocacy scheme, to providing information on promoting choice. Whatever your query we will try to help, or recommend someone else who can.

Members particularly value our training courses and we evaluate and monitor constantly to ensure we are meeting people's needs and providing good quality training.

Training courses this year includes:

- Communication and Advocacy, May 27 Newcastle
 - Ethics, Representation and Advocacy, September 2 London
 - Choice and User Involvement, November 9 Manchester
- We also design tailor-made courses where requested. Some recent in-house courses include:
- Communication and Advocacy training for Greenwich Citizen Advocacy;
 - Training in Advocacy for Social Care Professionals for social work and rehabilitation students at the University of Central England.

This year we will be producing a Skills Directory of members to make it easier for people to network with each other and share ideas, information and skills.

We have produced an Advocacy Learning Pack - Do The Rights Thing! - to enable others to explore the complex issues surrounding advocacy for people with sensory impairments and multiple disabilities. This pack comprises of a workbook of games and exercises and a reader of articles and essays. The pack costs £20 and is available from Communication Sales at the address below.

Our long-standing commitment to and involvement with advocacy continues to inform our work. We have developed innovative work around advocacy with people with sensory impairments and multiple disabilities who use Sense services. This includes encouraging the development of independent advocacy and providing information and training to staff and families. We also provide support to advocates supporting Sense service users and work in partnership with advocacy organisations across the country. We have just finished compiling an Advocacy Policy for the organisation. This policy demonstrates our commitment and enthusiasm to Sense service users having access to independent advocates. We believe independent advocacy enables people to have their voices heard and needs and rights recognised. It can also help them to have a stronger connection to the community.

We hope you would like to join us as a member of the Sense Advocacy Network and link up with others interested in advocacy for people with sensory impairments and multiple disabilities. Please contact me at the address below for further information.

Angie Lee-Foster

Advocacy Development Manager

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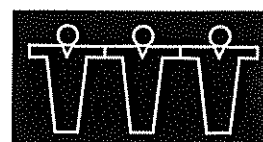
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"Every Circle is Different"

Sarah's Story is a fictitious account based on a number of true events.

Sarah is twenty five years old, living at home with her parents. Her older brother and younger sister have left home and are living in their own places. David is sharing a flat with a friend, Joanna is about to start her first year at university.

Like many other young people Sarah is thinking about her own future. The difference is that Sarah uses a wheelchair, has learning difficulties, and needs help to make future [plans. Her Mum and Dad are very supportive, but find it difficult to think of Sarah leaving home. AT the same time they worry about her long term future, as they know that the time will come when they won't be able to give her the physical support that she needs.

Because of these anxieties they helped Sarah to invite some people into her life to form a 'Circle of Support. They did this with assistance from friends and others who have experience of setting up and being part of people's 'Circles'.

Sarah's circle has now been established for over two years, they meet regularly and with Sarah as the focus, the heart of the circle. Together they plan her future by talking, exploring, dreaming and gathering information about where Sarah will live, what support she will need and how that support will be financed. They also help Sarah to think about work and educational opportunities. ?Sarah's plan is slowly developing, partnerships between the circle members and service providers and purchasers are being built and a big picture is emerging at a pace that Sarah and her parents are happy with.

In addition to planning for this major move, Sarah is busily involved with the here and now of her present life. People in the circle helped her discover a love of theatre and she now takes part in rehearsals with a local amateur dramatic group. She has always loved music and has started going to Blues events both locally and further afield. Now that Sarah is meeting people of her own age group through her various interests, she spends time hanging out with friends, shopping, listening to gossip, going to fun places and generally having a good time.

This ordinary life, which most families take for granted, was not something which was happening before the circle came about. Sarah's vulnerability, particularly as she doesn't use words, had meant that her parents were anxious about trusting people to spend time alone with her. They had always been her mainstay and had not experienced other people's involvement. It came as quite a shock when both her parents contracted flu and had to take to their beds at the same time. As in all our lives we are always unprepared for crisis. It happens, and isn't usually a big deal, but with their daughter's reliance on them for all her physical support needs it became a huge dilemma.

Every circle is as unique as the individual members. Sometimes they form around people who are in crisis and continue for as long as the person wants them to. We all think about and plan our lives in different ways. Some people

have very clear ideas about what they want and how to achieve it, others take opportunities as they arise.

Circles of Support are a way of helping people who want to make some changes in their life. It provides creative alternatives to the traditional ways of planning.

The service system tends to make the decisions, based on what is available within the system, meaning that people who have disabilities have had to fit into neat boxes, their careers mapped out from an early age - usually within a special and segregated system.

'Circles' puts the person at the centre and deliberately shifts power towards them, supported and assisted by those who love, like and know them well. 'Circles of Support' enable people to take control of their lives. Helping them to identify a desirable future, and developing a strategy to achieve it. They can help people to reclaim some of the freedom which most of us take for granted.

For Sarah, her circle is there, its members have helped Sarah get to know people and places in her own community, it has proved capable of coping through difficult times and will endeavour to continue to help Sarah plan for small and big events in her life, enabling her to have her hopes and dreams and a promising future.

Lynne Elwell, Partners in Policymaking

For further information about 'Circles of Support' contact the National Development Team.

Please

let us know if you have found any books, videos, equipment, playthings, leisure resources etc. that you think are particularly useful. Tell us about your favourite resources and how you use them, or any articles, books, videos or courses which have changed your way of thinking or of doing things.

VOICE FOR THE CHILD IN CARE (VCC) in SUNFIELD

Sunfield is a school and home for 120 children and young people with severe learning and developmental difficulties in the Clent hills near Kidderminster. The children are in 12 houses on the slope of the hill with a surrounding area of 60 acres. It is a beautiful setting.

It is recognised now how difficult it is for many children to live in a residential setting away from home - and how much harder it must be for those who have an added handicap of learning difficulties, particularly for those who have no speech and find it hard to communicate their thoughts and feelings.

The managers and staff at Sunfield are very keen to help all the children and young people to maximise their potential and to have access to all their rights. To this end they invited the VCC to provide a regular visiting service which started in September 1998. We were not strangers to the school because we had been providing an Independent Person service for their complaints procedure for a couple of years.

The VCC is a national organisation which was started in 1975. The name was taken from an article in the *Observer* written by Mia Kellmer Pringle, the founder of the National Children's Bureau, in response to the death of Maria Calwell, who was returned to her mother and step-father from a happy foster home and was subsequently killed. The VCC now visits young people in secure units all over the country and is in the process of setting up a service for children's homes. Sunfield is our first major venture into the world of disability. We felt we could rise to the challenge because we have a number of people in the area who have a great deal of experience of working in this field.

Visiting Representatives (VRs) are trained in advocacy but we retain the name Advocate for someone who picks up a problem and deals with it and then withdraws. The six VRs visit regularly once a fortnight and are gradually learning to communicate with the children and young people. They spend an hour in two homes each. It is not easy to explain about independence and children's rights to a child with severe learning difficulties. Whereas in other settings the VRs only take up issues on behalf of children and young people at their request it is necessary to be more pro-active in this setting and to raise matters with the managers which seem to be of concern.

There are regular support group meetings for the VRs every two months. A Link Person is responsible for liaison with the managers and staff and meets them regularly. The VCC has found it very important to do a lot of preparatory work with staff when setting up a service. If staff are not happy with the idea the children will not use it.

It is early days yet but so far the scheme seems to be working well. The VRs all feel that it is very worthwhile. Not unexpectedly those who visit the homes where the younger children live get more satisfaction than the VR who visits the two units for the older and more difficult young men. Fortunately we have a man with a great deal of experience who visits there.

On a recent visit to the school I was invited to visit the Award Assembly which takes place once a week and where achievement is celebrated. All the children were there and the Director, Professor Barry Carpenter, was leading them in singing. Most of the children are there because families and schools found their behaviour too challenging but Barry had them all in the palm of his hand and there was a wonderful atmosphere of friendship and happiness. What an achievement!

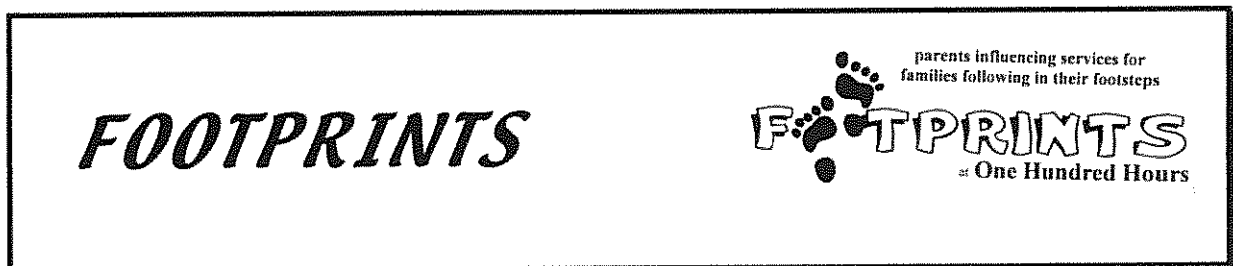
A Voice for the Child in Care

A national network of people committed to improving life for children and young people in care

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London N1 9PF

Graham Gibson
Regional Manager
Laneside
Church Road
Lilleshall
Nr. Newport
Shropshire TF10

9HE



Footprints - a free service from One Hundred Hours for groups of parents who want to give constructive feedback about services to their professionals. The aim is to influence services for the benefit of families coming along in the future.

If you work in a statutory or voluntary service what mechanism do you provide for listening to users? Do you really want to know how they perceive your service? Would such awareness inform the development of your service?

If you are a parent, how do you feel you can influence your local Social Services, Health Authority or Education Department? Can you get your voice heard in a constructive way or do you feel powerless?

The problem is formidable. Our Footprints project addresses these concerns and has the merit of being a simple process: when a group of parents want to take part they invite us to visit to listen to their experiences and views about services. We then relay this information in a written report to those local services. As far as we can, we foster an ongoing dialogue between the services and the parent group.

we can, we foster an ongoing dialogue between the services and the parent group.

With **Footprints** we have established the following principles:

- *Parents (and other users) do not have to wait to be invited to give feedback.*
- *Constructive feedback does not need to be confrontational. Footprints reports work for a better understanding by professionals of what life is like at home and how services impact on the family.*
- *Parents are resilient and altruistic. In our experience many parents, within months of the trauma of their own predicament, are feeling real concern for other parents they meet at clinics, etc.*
- *Parents are responsible and rational. Those professionals who don't want to ask parents what they want 'because they will ask for the moon' are underestimating parents' ability to come to sensible conclusions once they have good information.*
- *Parents' groups can work with service providers in equal partnership to give considered constructive feedback and to be consulted about change.*

Footprints is free to any group of parents of children with disabilities who want to give local service providers feed-back about services and how they could be improved (or ought to be maintained) for families in the future. A One Hundred Hours worker visits your parent group to talk with you about your needs and how these match (or don't match) with local services. Together we form these views, ideas, brickbats and bouquets into a Footprints report which we will then distribute to the local service providers you feel are relevant. As individual parents, you will not be identifiable in the report but as a group, you will have a strong voice.

These quotes are taken from recent Footprints sessions which are happening around the country:

We want things to be different for families following in our footsteps ...

"...The assessment report the Child Development Centre wrote about my child wasn't very fair. It just listed all the negatives."

"...When my baby was born with problems, I wasn't given any support. I was left to sort it out for myself. It was like being pushed out into a world of my own. I feel a whole year was wasted."

North of England Parents

"...we were sent home from hospital with lots of questions and no answers. At home, there was no-one supporting me. Those two years were the worst years I have ever had."

...but it isn't all negative ...

"...the woman from Portage came to us. I found her really useful and very helpful. She just used to come and listen to me every week. Sometimes she looked after my other child so I could spend time with Jonathan."

Midlands Parent

If you are interested in a Footprints scheme in your area, please call
Peter Limbrick on 01706 819200

report back ...

National Focus Group Seminar on Advocacy and Representation

The third seminar organised by Mencap National Focus Group was held on 28th April and was chaired by Prof. Barry Carpenter, Chief Executive of Sunfield School.

The seminar opened with a presentation by Loretto Lambe Projects Director of PAMIS, who has been involved with the advocacy movement for many years. She introduced the various forms of advocacy, and distinguished between formal advocacy, and the informal advocacy which is inherent in services and schemes which are set up for the benefit of other people. So her first question was: **Advocacy - what does it mean?**

"Advocacy is to speak and act, to secure the rights and services a person (or persons, including yourself) is entitled to, or requires."

She then gave a brief history of the advocacy movement from its beginnings in the 1960s and described the key elements of the different models of advocacy which are recognised by the international advocacy movement. Although people with PMLD may use any one of the models she described, Citizen Advocacy is generally the most appropriate form for them.

Citizen advocates are volunteers (unpaid) who act independently to further the interests of the person they represent. The citizen advocate's role is to:

- enable their partner to be heard and respected
- uphold and represent the interests of the partner as if they were their own
- respect their partner's right to privacy and confidentiality
- act as an authorised representative
- ensure that their partner has her/his place in society as a valued citizen.

She then went on to describe two major facets of citizen advocacy: *instrumental* advocacy which is essentially task centred and problem solving; and *expressive* advocacy which is primarily about forming a friendship, offering support, sharing leisure, family or friends' time and helping someone to become involved in the life and social networks of the local community.

Both the expressive and instrumental roles should have equal weight. In practice an advocate may devote much more time to the expressive role, particularly at the beginning of a partnership when the partners are getting to know each other and understand each other's communication systems. However time must always be spent on the instrumental role to ensure that their partner's rights are upheld and that they receive whatever help and support they need. It is also important that the advocate provides information or ensures that she/he has access to information in order that choices made are informed. The advocate should also strive to ensure that their partner has opportunities to experience a range of settings that will help to both widen their network and help in choice making.

Each Citizen Advocacy projects work to agreed broad principles:

- *No conflict of interest* - the scheme should be independent of service providers.
- Advocacy relationships (partnerships) are on a *one-to-one* basis.
- Partners have *equal status*.
- *The instrumental and expressive roles have equal weight*
- Advocates should receive training.

This comprehensive survey of different forms of advocacy was followed by Lynne Elwell giving a personal and professional account of Advocacy in Practice, and in particular Circles of Support.

Advocacy in Practice

Lynne gave a most interesting and lively talk based on her work as a Disability Rights Advocate, and as a parent. She started by talking about 'labels' and that, although they have their use at times, in general they have considerable disadvantages:

- They close doors to people
- People become experts in a particular label
- There may be several children in a family but the child with a label gets extra attention,
- People with labels become 'collectables' for example, someone with a particular label is needed for a house in the community.

Lynne suggested that society separates out people, and this ensures that those with profound disabilities are always at the end of the queue for services or benefits. She talked about the different ways of describing people - either a person is a "can't do" or a real person. She described how difficult she had found it to get support for her daughter because she was always described as a "can't do". She states that there needs to be a change from

"is the person ready to ...?" to *"What would it take to ...?"*

She recounted some of the difficulties she had as a parent:

That systems don't work and people need citizen advocates who can 'hold the hand' of the person who has been put beyond the social boundaries and bring them back using ordinary language and in ordinary ways.

Professionals "will not listen to me - I'm her mother" and therefore people with disabilities need independent advocates.

People with high support needs are always seen with paid staff and not with friends, therefore it is very important that citizen advocates are volunteers and are not paid.

Lynne then talked about *Circles of Support* and introduced the four circles of connectedness described by Judith Snow. These are:

Intimacy
Friendship
Participation
Economic exchange.

Everything we do involves interacting with other people at some level. Circles of support can provide people with support to live their own lives and attain some of their dreams.

Questions and discussion following the presentations brought up a number of issues, and comments from parents point up the frequent, almost inevitable, conflicts with professionals in the services. Other parents described how, over a long period of time they had found that by adopting a conciliatory approach, they achieved the changes they wanted.

In the afternoon participants worked in two groups to discuss two main issues:

1. Communication, advocacy and representation
2. How services promote working together.

THE WORK OF THE FOUNDATION FOR PEOPLE WITH LEARNING DISABILITIES

For 50 years the Mental Health Foundation (MHF) has funded projects and research, and pioneered approaches to the care and support of people with mental health needs and people with learning disabilities. Then last October, the Foundation for People with Learning Disabilities was set up as distinctive part of the MHF. This reflected the development of our work in recent years.

How can people with profound and multiple learning disabilities be supported to make choices in their lives? This is the question posed by the Choice Initiative, a two year programme of five projects, exploring the ways that people with severe, profound and multiple learning disabilities can be supported to express their wishes and bring changes to areas of their lives. The British Institute of Learning Disabilities is being funded to research and write a training pack for citizen advocates. The other four projects are exploring choices during the transition from school, in employment, in friendships and in accessing community activities. If you would like to know more about the Initiative, we publish regular free bulletins. We have also held a conference - Communication Matters - in March 1999.

The GOLD programme of action research, looking at the needs of people as they grow older with learning disabilities, has recently started. We publish a regular bulletin - Gold Nuggets.

The Foundation also provides free information leaflets. There are two in the series: 'Learning Disabilities and the Family' and 'The Young Child and the Teenager with Severe Learning Disabilities'.

The emphasis in our work is to explore innovative ways to support people and to communicate our findings widely. Please contact me if you would like to receive our bulletins, to attend our conferences or to know more about our work.

Hazel Morgan, Programmes Manager
The Foundation for People with Learning Disabilities
20.21 Cornwall Terrace
London NW1 4QL

practical ideas

"Re-cycled Resource"

Margaret Power has sent in this idea and writes "An old bicycle wheel, any size, can be an effective source of sound stimulation. Place the wheel on its side, supported by any suitable vertical rod which will fit its hub so that it can turn freely. A drumstick held loosely over the revolving spokes makes a wonderful harp-like sound.

Encourage experiments which will change the sound -
vary the *speed* of the wheel
vary the *position* of the stick on the wheel
try *different 'sticks'* such as a metal rod or spoon
Coloured spokes could be an added incentive!

letters ----

pamis

Profound and Multiple Impairment Service
White Top Research Unit
Frankland Building, The University, Dundee, DD1 4HN, Scotland
Tel: 01382 345 154 Fax: 01382 227464
e-mail: pamis@dundee.ac.uk
web site: <http://www.dundee.ac.uk/pamis/>

26th April 1999

Dear Colleague

Changing Facilities in Public Toilets for People with Disabilities

I am writing to ask for your support in PAMIS' campaign for changing facilities in public toilets for people with disabilities.

PAMIS is a voluntary organisation working with families who care for people with profound and multiple learning disability. We aim to provide up-to-date information and practical help on all aspects of care, therapy, rights and entitlements. Increasingly, PAMIS is campaigning for better services to ensure that people with this degree of disability and their family carers have access to the activities and opportunities open to the rest of the community.

Family carers have made it clear that one of the most restrictive practical barriers is the lack of suitable changing facilities in public toilets for older children and adults with incontinence problems. All too often, families find themselves having to change their daughter or son on a toilet floor, a very undignified and uncomfortable and unhygienic process for the person with disabilities and one which carries serious risk of damage to the carer's back. The alternative is to simply stay at home.

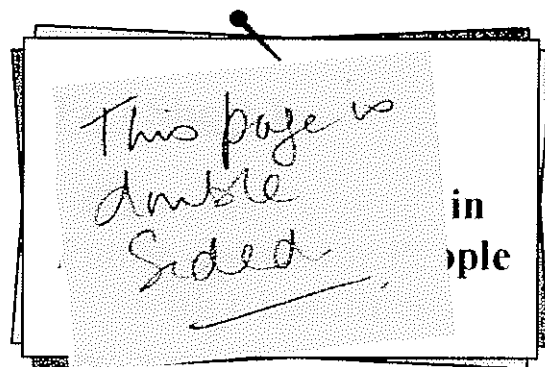
PAMIS has been actively campaigning in Scotland for better changing facilities and has produced a factsheet, based on recommendations from physiotherapists and occupational therapists (copy enclosed). We are now seeking to widen our campaign to the UK as a whole. We also think that other groups such as the frail elderly and their carers may well share these problems and benefit from better facilities.

These difficulties faced by family carers are probably very familiar to your organisation, and we would welcome your support in this campaign.

PAMIS will be represented at the British Toilet Association Public Toilet Seminar on 11 May, which will be attended by service providers, users groups and manufacturers and will be making the case for provision of changing facilities there. Please contact me if you would like to discuss the campaign.

Yours sincerely

Jessie Roberts
Project Co-ordinator



Access: Everyone's Right

People with profound and multiple disabilities and their family carers have a right to full integration in the community, and to be able to enjoy activities others take for granted: for example, shopping trips, visits to museums or exhibitions, to the park or to the swimming pool.

However, family carers face a number of serious access problems on a daily basis. Many of these can be almost insuperable obstacles to taking their daughter or son out. The result is social isolation and loss of stimulus for the person with disabilities - and often for the principal carer and for other members of the family too.

The Need for Changing Facilities

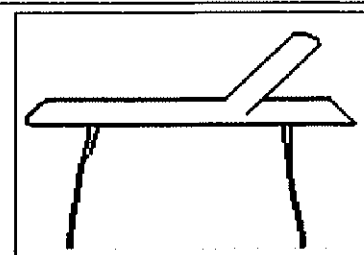
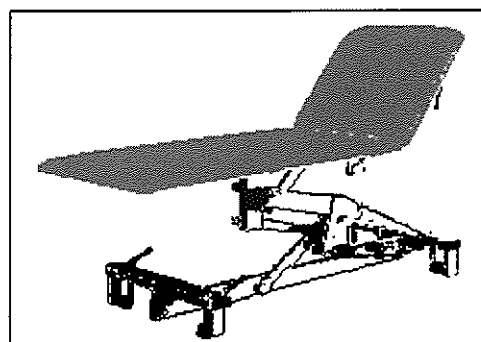
Lack of suitable changing facilities in toilets for the disabled is one of the most restrictive practical problems preventing families from going out. Families caring for someone who is incontinent describe having to change their daughter or son on toilet floors: not only is this undignified and unhygienic, it is also involves heavy lifting with the potential risk of serious damage to a carer's back. To avoid this situation, many families opt to stay at home if no changing facilities are available.

What is needed

Changing Benches

The solution is the installation of a changing bench in public toilets for people with disabilities. There are two types suitable for older children and adults:

- the *free-standing plinth/couch*, as used in physiotherapy departments. This type of changing bench is raised and lowered by a hydraulically operated foot pedal. This is definitely the option recommended by physiotherapists, occupational therapists and carers. A two-section plinth with a washable padded surface and a pair of 'cot sides' for safety is most suitable.
- the *folding type*, mounted on a wall, which hangs flat when not in use. This type of bench is useful for a confined space and should be installed for use at the height of the average wheelchair seat, i.e. 450 mm.. However, because it is not height-adjustable, the bench is then at an unsuitable working height for most carers' backs.



FUTURE FOCUSInclusion

The theme for the next issue of PMLD-Link is inclusion, and we would like to hear how successful you are being at including people with PMLD in activities with their less-disabled and non-disabled peers in your school, daycentre or residential provision.

Inclusion has been defined in a number of ways, but this relatively recent definition provided by Hall (1996) gives the flavour of a number of similar definitions:

"Being a full member of an age-appropriate class in your local school doing the same lessons as the other pupils and it mattering if you are not there. Plus you have friends who spend time with you outside school".

But inclusion is a controversial topic and one which gives rise to strong emotions, and such specific definitions are not necessarily the most helpful to those who are trying to ensure that people with PMLD are able to live as full and meaningful a life as possible.

We would like you, therefore, to interpret the concept far more widely in sharing your experiences of including people with PMLD. We are interested in hearing about the range of ways in which people with PMLD are being enabled to learn and to participate in the community with people of all abilities and disabilities.

There have been considerable developments in inclusion over recent years. For example, in the field of education a number of authorities have closed some of their special schools and are providing for almost all pupils in mainstream settings of one sort or another. The fact remains, however, that those pupils who remain in specialist settings are likely to be those with the most complex needs, including those with PMLD. Furthermore, some nominally inclusive settings actually provide few opportunities for their pupils to interact or learn together while others, which appear to be highly segregated, are running successful inclusion projects (Julian and Ware, 1998).

Are these experiences paralleled in other services for people with PMLD?

Is closure of special schools necessarily the best way to ensure inclusion for pupils with PMLD, or the use of generic services the most effective way to ensure community involvement for adults?

What are the barriers to inclusion and how successfully can these be overcome?

What are factors which make for success in an inclusion project?

Writing in relation to schools, Wedell (1995) has highlighted another paradox, that is, that many schools are unsuitable learning environments for some of their current pupils due to a failure to take account of the full range of pupil learning needs, so we can end up trying to include people in precisely the sort of education which we do not regard as suitable for their needs. This dilemma is likely to be particularly acute in relation to those with PMLD.

And what about the evidence that some people with PMLD have problems coping with unfamiliar people and situations; and conversely that they seem to learn best in specially adapted environments (eg. Byers, 1998)? Can making adequate provision for these needs be reconciled with more inclusive environments?

These are just some of the difficult practical concerns which are raised when we think seriously about the inclusion of people with PMLD. Please let us have your accounts of your experiences in this area, and your suggestions as to the way forward.

Dr. Jean Ware, Lecturer, School of Education, University of Wales, Cardiff (on secondment to the Special Education Department, St. Patrick College, Dublin)

References

Byers, R. (1998) Managing the Learning Environment in P.Lacey and C.Ouvry (eds) *People with Profound and Multiple Learning Disabilities: A collaborative approach to meeting complex needs*. London: Fulton

Hall, J. (1996) Integration, Inclusion - What does it all Mean? in J. Coupe o'Kane and J.Golbarte (eds) *Whose Choice? Contentious Issues for Those Working with People with Learning Disabilities*. London: Fulton

Julian, G. and Ware, J. (1998) Quality inclusive provision for pupils with profound and multiple learning disabilities? Presented at the BILD Conference, Eastbourne, September 1998

Wedell, K. (1995) Making Inclusive Education Ordinary. *British Journal of Special Education* 22(3) 100-104

reviews *reviews* reviews *reviews*

Multisensory Environments
Pagliano, P.

London: David Fulton 1999
176 pp Paperback £16.00
ISBN 1-15346-553-4

This book fills a gap felt by many practitioners using any form of multisensory environments (MSE) with children or adults in therapeutic, recreational or educational settings. It offers a theoretical background to support the responses we have observed and 'gut feelings' we may have experienced when using MSE especially with individuals who have PMLD.

Pagliano hopes that by providing a critical review of the disparate issues surrounding MSE use, we will be able to rise to the challenge of tailoring the environment to meet the perceived needs of the individual.

The book addresses the issues in four sections. Part I is an introduction to the field. It draws extensively on the literature to draw up working definitions and a theoretical framework which the rest of the book develops.

Part II concentrates on Design and Construction. Types of rooms (e.g. dark room, soft play room etc.) and their functions are thoroughly explored,

with facilities and resources listed. Practical aspects of planning (including Health and Safety issues) are covered along with the roles and value of a collaborative team approach.

Part III has a curriculum development focus and refers to a range of special needs. Of particular interest are the chapters on assessment and curriculum approaches for pupils with SLD/PMLD and the more specific ideas for maximising available vision and hearing for these individuals.

The final section 'Future Developments' takes a very constructive stance in its aims to encourage practitioners to embark on some research into MSE use.

This is a valuable source of information for those in any setting, using MSE. It certainly provides the 'where-with-all' to inspire and instruct more creative and accurately tailored use of any MSE. At one level it offers some very practical ideas and over 30 continua by which differing needs can be responded to. At another level there are

sound, theoretical models on which to base a whole-school or centre approach and, at a further level, it lends itself for those wanting to study any aspect of MSE in use in greater depth.

Pagliano has put together a very interesting book that raises many pertinent issues far beyond the specific focus of MSE. At first I found the format unusual in the way very specific practical suggestions are set alongside some very thought provoking analysis of theory. However I was soon accustomed and able to read through or dip-in to particular topics. Pagliano has an easy writing style and explains his ideas clearly.

Returning to his final aims in persuading us to reflect and share our own practice; he offers clear guidance on the 'how' and 'what' to do. PMLD-Link provides the ideal forum for the next stage of sharing your findings. Over to you now!

Ann Fergusson
May 1999

RESOURCES

NEW BOOKS

Multisensory Environments by Paul Pagliano. Published by David Fulton (1999) ISBN 1-83546-553-4 This book is reviewed in this issue.

Using Television and Video to Support Learning: A Handbook for Teachers in Special and Mainstream Schools edited by Steven Fawkes, Su Hurrell and Nick Peacey. Published by David Fulton (1999). ISBN 1-85346-597-6

Lifemaps of People with Learning Disabilities Barry Gray and Geoff Ridden. Published by Jessica Kingsley Publishers, 116 Pentonville Road, London, N1 9JB

Learning and Inclusion: The Cleves School Experience edited by Priscilla Alderson and written by the staff and pupils of the Cleves School, Newham. Published by David Fulton (1999) ISBN 1-85346-609-3

Ageing Matters: Pathways for Older People with a Learning Disability. Managers' Reader. by Steve Moss, Loretto Lambe and James Hogg. Published by BILD (1998) ISBN 1873791 39 9

People with Profound and Multiple Learning Disabilities: A Collaborative Approach to Meeting Complex Needs edited by Penny Lacey and Carol Ouvry. Published by David Fulton (1998) ISBN 1-85346-488-0

JOURNALS Etc.

Ethics and Intellectual Disability - Newsletter of the Network on Ethics and Intellectual Disability. Mailing list: Prof. de Johannes S. Reinders, Institute for Ethics, Free University, Amsterdam, The Netherlands or Robert M. Veatch, Joseph and Rose Kennedy Institute of Ethics, Georgetown University, Washington, DC20057, USA

COURSES AND CONFERENCES

1999

JULY

9th

Loss, Change and Grief - Helping Children

Organised by: Sunfield Professional Development Centre
Venue: Sunfield Professional Development Centre
Leader: Erica Brown
Further details: Jackie Wadlow
Tel: 01562 883183
e-mail: jswadlow@sunfieldsch.u-net.com

9th

Commitment to Change

Conference for health professionals to improve the way they talk to parents about a child's disability.
Run by: SCOPE with ENB and Nene University
Venue: Nene University, Northampton
Further details: Tel: 01908 243619

SEPTEMBER

7th

Cultural Issues in Sexuality Work with People with Learning Disabilities

Organised by: CONSENT
Venue: Harperbury, Radlett, Herts
Leader: Seema Malhotra
Further details: CONSENT
Tel: 01923 670804

- 13th to 15th **bild Annual Conference - Frontiers in understanding learning disabilities**
International conference highlighting the implications of current research for future practice. Guest speakers of international repute; symposia presentations; poster sessions, workshops and seminar papers.
Organised by: BILD
Venue: Church House, Westminster, London
Further details: Karen Clarke
Tel: 01562 850251
e-mail: Karen.Clarke@bild-edn.demon.co.uk
- 14th to 16th **Better Breaks for the 21st Century**
Second international conference on short term (respite) care which will focus on innovative models of community based short term care for children and adults. Keynote speakers, seminars, interactive workshop presentations and exhibitions.
Organised by: Shared Care Network and Barnardos
Venue: Canterbury
Further details: Shared Care Network, Norah Fry Research Centre
Fax: 0117 946 6553
e-mail: v.jones@bristol.ac.uk
or c.e.robinson@bristol.ac.uk
- 17th **mencap National Learning Disability Conference**
Learning for Life: Education for 5-16 year olds with learning disabilities.
Organised by: Mencap
Venue: Bournemouth International Centre
Further details: NG Events
Tel: 011449 673723

OCTOBER

- 7th **Communication - It's More Than Words**
A workshop on the process of giving and receiving effective communication when working with adults with learning disabilities.
Organised by: Orchard Hill College of FE
Venue: Orchard Hill College
Further details: Andrew Lindup
Tel: 0181 770 8125
- 15th **The Rett disorder and the developing brain.**
One day conference with presentations covering wide ranging issues in the understanding of the Rett Disorder.
Organised by: Mac Keith Meetings
Venue: Royal Society of Medicine, London
Further details: Kate Lindley, Royal Society of Medicine
Tel: 0171 290 2900 x 4907
e-mail: kate.lindley@roysocmed.ac.uk
- 15th **Literacy and numeracy for pupils with PMLD**
Realistic learning and teaching approaches - a one day seminar.
Organised by: Catalyst Education Resources Ltd.
Venue: Newcastle upon Tyne
Leader: Flo Longhorn
Further details: Catalyst Education Resources Ltd.
Tel: 01234 764108
- 16th **On Target!**
Observing, Assessing and Targeting Effective Environments of Learning for Pupils with Profound and Multiple Learning Difficulties - a one day seminar.
Organised by: Catalyst Education Resources Ltd.
Leader: Flo Longhorn
Venue: Durham
Further details: Catalyst Education Resources Ltd.
Tel: 01234 764108

19th Literacy and numeracy for pupils with PMLD
 realistic learning and teaching approaches - a one day seminar
 Organised by: Catalyst Education Resources Ltd.
 Venue: Preston
 Leader: Flo Longhorn
 Further details: Catalyst Education Resources Ltd.
 Tel: 01234 764108

NOVEMBER

3rd On Target!
 Observing, Assessing and targeting effective environments of learning
 for pupils with profound and multiple learning difficulties -
 a one day seminar
 Organised by: Catalyst Education Resources Ltd.
 Leader: Flo Longhorn
 Venue: Manchester
 Further details: Catalyst Education Resources
 Tel: 01234 764108

4th Literacy and numeracy for pupils with PMLD
 Realistic learning and teaching approaches - a one day seminar
 Organised by Catalyst Education Resources Ltd.
 Venue: Liverpool
 Leader: Flo Longhorn
 Further details: Catalyst Education Resources Ltd.
 Tel: 01234 764108

9th On Target!
 Observing, Assessing and Targeting Effective Environments of
 Learning for Pupils with Profound and Multiple Learning Difficulties -
 a one day seminar.
 Organised by: Catalyst Education Resources Ltd.
 Leader: Flo Longhorn
 Venue: Liverpool
 Further details: Catalyst Education Resources Ltd.
 Tel: 01234 764108

11th Literacy and numeracy for pupils with PMLD
 realistic learning and teaching approaches - a one day seminar
 Organised by: Catalyst Education Resources Ltd.
 Venue: Central London
 Leader: Flo Longhorn
 Further details: Catalyst Education Resources Ltd.
 Tel: 01234 764108

12th Multisensory Education for Learners with Special Needs
 A one day workshop for learning support assistants in sensory
 development and education.
 Organised by: Catalyst Education Resources Ltd.
 Venue: Central London
 Leader: Flo Longhorn
 Further details: Catalyst Education Resources Ltd.
 Tel: 01234 764108

2000

FEBRUARY

18th Arts for Adults with Disabilities - Musical Interaction - Towards
 to Numeracy
 20th A trio of opportunities for exploring ways in which music can be used to
 promote enjoyment and learning. For music specialists and generalist
 teachers.
 Organised by: Special Music Courses
 Venue: Great Hucklow, Derbyshire
 Further details: Kate Baxter
 Tel: 0115 9609528

MARCH

25th Arts 2000?- Where are the Arts now for children with special needs?
This conference will address the question in a dynamic and practical way that will take Arts in the Curriculum forward for children with special educational needs.
Organised by: Sunfield Professional Development Centre
Venue: Sunfield Professional Development Centre
Further details: Jackie Wadlow
Tel: 01562 883183

JULY

24th to 28th ISEC 2000 : Including the Excluded: International Special Education Congress 2000
An opportunity for people involved in special education from around the world to hear about best practice and new ideas, share knowledge and information in more practical ways, visit local facilities.
Venue: University of Manchester
Further details: Prof. Peter Mittler
e-mail: isec@man.ac.uk
or Congress Secretariat:
Tel: 01942 608374

LEARNING PACKS

Sex in Context:

Strategies and safeguards relating to the sexuality of children and adults with profound and multiple impairments. Caroline Downs and Ann Craft
Materials in two parts which provide information and exercises which enable staff to work with their service user's, and to work productively with parents and carers.
Additional Handbook designed to facilitate review of service policies and to develop guidelines.
Pavilion Publishing, FREEPOSE BR 458, 8 St. George's Place, Brighton, BN1 4ZZ

Approaches to People with Profound and Complex Disabilities.

Values-based approach to working with people with disabilities which helps staff to develop an understanding of the nature of profound and complex disability through examining the needs of clients and exploring the main strategies for improving professional practice.
Pavilion Publishing, FREEPOSE BR 458, 8 St. George's Place, Brighton, BN1 4ZZ

Approaches to working with children with multiple disabilities and a visual impairment

Educational pack for staff working with this group of children. Focuses on how visual impairment affects learning, and gives practical ideas and ways of working.
Produced by VITAL.
Published by RNIB, PO Box 173 Peterborough PE2 6WS Tel. 0345 456457

BILD Independent Study Courses

These training materials set out to help staff and first line managers meet the care and support needs of different groups of people with a learning disability. They are designed to help staff develop knowledge and skills which reflect best practice in a variety of care settings. The materials can be used in a variety of ways: for independent study by individuals; to support training organised by a service or agency; as resource materials. These courses are accredited with the Open College Network. Of particular relevance to those working with people with profound learning disabilities are:

Better Choices - Fuller Lives for People with Profound Learning Disability
Ageing Matters: Pathways for Older People with a Learning Disability

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

University of Birmingham School of Education in conjunction with BILD

Further details: 0121 414 3466

M.Sc/PG Diploma in Learning Disability Studies

Commencing September 1999 - 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: Stuart Cumella or Helen Bradley,

Department of Psychiatry, Queen Elizabeth Psychiatric Hospital, Mindelsohn Way, Edgbaston, Birmingham B15 2QZ Tel: 0121 627 2853

Profound Learning Disability and Multi Sensory Impairments

Two year distance learning course combined with workshops.

For people who are involved with children and adults who have complex learning needs and sensory impairments.

Offered at three levels: Certificate, Advanced Diploma and Masters.

University of Manchester Faculty of Education in conjunction with Royal Schools for the Deaf, Manchester.

Further details: 0161 437 3577

EXHIBITIONS

7th July 1999 ***RNIB Vision 99***

The RNIB exhibition for blind and partially sighted people.

Venue: New Century House, Manchester

Further details: Jennifer Makin

Tel: 0171 388 1266

PLANET will be attending the following events and exhibitions:

15-16 Sept. Independent Living London

Venue: Wembley Exhibition Centre

Further details: Ticket HOTline

Tel: 01275 836 465

17-19 Sept. Nursery World Under 8's

Venue: Olympia, London

Further details: Nursery World

Tel: 0171 782 3136

4-6 Nov. Special Needs London

Venue: Business Design Centre, Islington

Further details: The Publishers Association

Tel: 0171 565 7474