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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

Summer/Autumn1998

Many readers may be wondering if they have missed a copy, or if their subscriptions have run out because this issue is very late - for which apologies.

The topic this time is on ethical issues and dilemmas which parents, carers or practitioners may meet in the course of caring and working with someone who has PMLD. Even the daily event of making choices involves a dilemma for many people who are supporting individuals with PMLD because of the difficulty of being sure that their wishes are interpreted correctly. Understandably, people have been reluctant to write about such a difficult and sensitive issue, so even greater thanks than ususal to those few who have courageously done so, and particularly to the parents who have written articles about their experiences, for whom these decisions have an added dimension.

Christina Tilstone has writen from the point of view of school practice in her article on the ethical issues involved in the use of observation, highlighting the difficulty of maintaining privacy and dignity for school pupils while, at the same time, finding out as much as possible about each one to ensure that educational provision is as effective as possible. Surely this dilemma also applies to adult services where observation is used for assessment and monitoring.

As usual we have articles on other topics - one from Ireland by Michael Shevlin gives a picture of how inclusion is being approached in one area. There is also information about resources and feedback from conferences and seminars which have taken place recently. If you have been to any of the courses which are listed at the back of this issue, or any other course or event which focused on the needs of people with PMLD do let us know - just a short paragraph would be enough to put in our ***report back*** section.

BUSINESS MATTERS

Articles:

In **Future Focus** Loretto introduces the next topic - Music, Movement and Dance. With Christmas productions and parties there must be a lot of this going on at the moment - and what about the wealth of music and dance from other cultures? Please write about it and allow us to share in your celebrations or exciting experiences! Of course, articles on any other subject are also very welcome, so if this issue triggers any thoughts you would be prepared to share with us, or if you have any other experiences, ideas or questions you would like to air, put pen to paper and write!

I am hoping that the next issue will come out well before Easter and material to be included should reach me by the *middle of January*. If possible, can you send articles with good margins in single line spacing printed on one side of the paper only. However, if you can't do this don't let it prevent you from writing - as long as I can read it I can type it up. Illustrations are welcome, although photographs are difficult to reproduce well. I look forward to hearing from you with your contributions!

Subscriptions

These are now due for 1998/99 which includes Winter, Spring and Summer/Autumn issue Nos. 32, 33 and 34. There is a separate subscription sheet with this copy so you don't have to tear off the back page this time. If you have already sent your subscription, pass the it on to someone else who might be interested.

BUT PLEASE - if your subscription is paid by your local authority tell them to tell me who they are paying it for. I get a number of cheques from local authorities with no indication of which school or centre it relates to and this involves long and convoluted telephone calls to find out the name of the subscriber. The renewal form is best, but just the name of your organisation will do. Thanks.

Carol Ouvry
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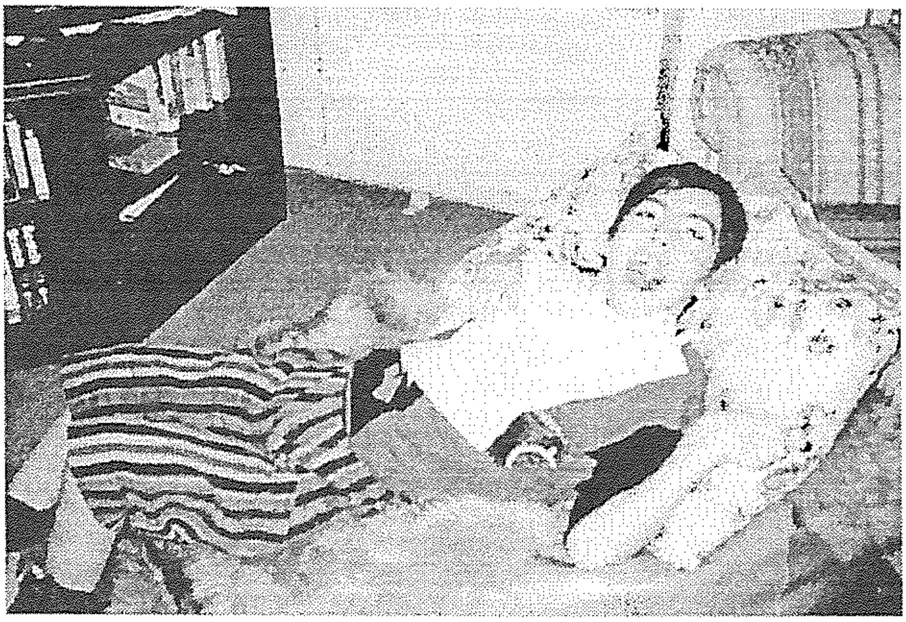
Ethical Decisions: Parents' Dilemmas

My son Craig is 11 years old and has cerebral palsy, epilepsy and profound learning disability. Physically he demands a great deal of my strength but I find it a pleasure to care for such a lovely, happy individual. He has a gentle temperament, a joy of life and a love of people. Throughout his short life to date I have been put in the position of having to take serious decisions about his physical and mental welfare without being able to bring him fully into the decision making process. Most parents in my position will find this almost a day to day occurrence.



Craig relaxing at home.

Having read the *Future Focus* article on 'Ethical Issues' in the last PMLD Link, I concur that the Law, at present, does not assist parents in reaching decisions and there is a need for clearer legislation to support everybody involved in the decision making process. However, we do not want so restrictive a Law that we lose sight of the individual's right to autonomy. All parents must become proactive in the current debate on the proposed new legislation and not leave it totally in the hands of the professionals, who now have a duty to ensure that parents, carers and advocates of people with PMLD are fully involved. Those who are more able must also have their views heard.

Some Examples of Ethical Decisions

From infancy I have had to give my permission for Craig to have multiple blood tests, X-rays and numerous drugs. All these may have medical repercussions on my son but I am left with making a decision on an immediate basis, often without time to discuss the options (if any) with anyone else. Although - because he is still a minor - there is no legal difficulty, I am still faced with the moral and ethical dilemmas, but in the scale of (ensuing) more serious medical difficulties that Craig has faced, these were 'minor' issues.

Four years ago I was confronted with the major decision of whether to permit a gastrostomy and fundiplication operation to be carried out on my son. He had always had enormous feeding difficulties and there was real concern that he was aspirating food particles into his lungs.

During 1993 Craig fell seriously ill with a herpes virus which left him totally unable to feed or take in his required drugs. He was put on to a nasal-gastric feeding tube and a drip for fluids and drugs. It was at this time that the gastrostomy option was put before me. During his stay in hospital I was given the opportunity to meet another youngster with a gastrostomy and saw at first hand the benefits that this could give to a child with PMLD and extreme feeding difficulties. Following a consultation with his surgeon, who outlined with great honesty the 18% risk of death or serious adverse reactions during the operation, I had to make a decision. This was helped in part by the 24 hour reflux investigation and Barium Test which proved conclusively and very dramatically that he aspirated food and liquids - there are still specks of Barium in his lungs.

There followed weeks of agonising on the morality and ethics of taking such a serious decision without my son being able to understand why I was agreeing to a procedure that would affect his life, that would be painful and uncomfortable and could have long-term implications for him. After another consultation with his surgeon where I asked him honestly, *"if Craig was his child would he have the operation"*, and following his emphatic *'yes'*, I then signed my consent for the operation to go ahead. The operation was timed for the following Summer, July 1994, and during this waiting period I often reflected on my decision, both positively and negatively. The operation was successful and Craig is now a much happier and healthy young boy.

Involving Others in Moral and Ethical Decisions

Due to the enormous pressure I felt in having to come to such a major decision on my son's immediate and future welfare I explored the possible benefits that Craig might gain from having his own proactive independent advocate. I am very pleased that I followed this course as he now has a Citizen Advocate and this has certainly reduced some of the pressure that I have felt in the past. Her involvement in Craig's life is purely to speak on his behalf and interpret his wishes. Recently she supported Craig and myself during a consultation to decide whether my son would benefit from an operation on his knee tendons. After listening to the pros and cons we decided jointly that Craig would not benefit from the operation at this time. However, ultimately I had to make this decision.

Craig's Citizen Advocate is not just involved with us in medical dilemmas but in many other areas of decision making that affects Craig's life. For example, recently she spoke up for him when there was the possibility that Craig's respite arrangements could be altered. She knew instinctively that this would cause a great deal of upset for him and contacted the relevant Social Work Department to represent his views.

Future Decisions .....?

The examples I have given are but a few I have had to cope with over the years. These obviously will increase and become more complex as the years go by. Who will speak up for Craig and voice his views once he reaches adulthood? In the eyes of the Law, once he reaches 18 years, he will be deemed to be able to make his own decisions. Everyone knows that this is not a reality for Craig and for other young people like him. He really cannot give informed consent on complex issues such as I have described. Parents are put in the position of having to take 'illegal' decisions. Our children deserve a better service from the legal framework. This cries out for the empowerment for our Citizen Advocacy services and true recognition in law of their authority to be seen as a positive informed representative of their advocacy partner. Until we have legislation that clearly recognises the rights of both the person with PMLD and those of their parents, carers and advocates, we, the parents will have to continue to carry the burden of responsibility of making profound decisions for our children.

PMLD Link - a discussion forum for parents ?

I would be delighted to hear from other parents as to how they deal with the dilemmas we all face daily. I have the opportunity to raise all sorts of issues with other parents and professionals in our PAMIS Special Interest Group where we share and exchange information and, collectively campaign for better services and equal opportunities for our daughters and sons with profound disabilities. Other parents may not have such and outlet. We could set up a *'parents discussion forum'* through PMLD Link - what do you think ? In this article I have concentrated on some of the ethical decisions we as parents are faced with and have not covered the discrimination issues that were raised by Judith Cavet in her Future Focus. This is a also a very important topic for parents and one I would like to come back at a later stage.

If anyone wants to contact me direct about any of the points I have raised you could write to me c/o the PAMIS office, the address is:

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I have based this article on a much longer paper I delivered on 30 September 1998 to a conference at the Royal Society of Medicine, London, on the topic of *Theoretical and practical approaches to the management of eating and drinking difficulties in people with learning disabilities from infancy to adult life.*

A Voyage of Souls - Holiday with Johanna

The question I asked myself was - how to avoid this sounding like Enid Blyton - 'The Four go Youth Hostelling with a Wheelchair'. The story has a beginning, a middle but no end.

Johanna is 13 years old, 5 foot 2 inches, 38 kgs. and tough. She has profound multiple disabilty, no commonly accepted language and is wheelchair bound, requiring a waistcoat harness for postural support. She is very beautiful. She has a brain abnormality and consequently has epileptic seizures at times day and night. She takes anti-convulsant drugs that control this to a questionable degree. In May 1997 she had a Vagal Nerve Stimulator implanted, the latest in micro chip technology that, in simple terms, acts as an epileptic pacemaker. This has helped in preventing frequent episodes of Epileptic Status that required hospital treatment. (14 weeks in hospital in 1996). Since June this year Johanna has a gastrostomy that helps to keep her nourished and hydrated.

Having felt that we had organised medically what we could for her we have begun to feel more confident and in control. Hoping that we have given her the best chance to experience a reasonable quality of life. In August '98 we decided not to leave her behind in respite care while we snatched a weeks holiday with our other daughter Esther (11), but to have two weeks and take Jo with us. We would ride the waves together so we headed for the surf of the Pembrokeshire coast. Body boards wedged beside the wheelchair, alongside pads and gastrostomy tubes. A case of Nutrison on top of a case of red wine promising not to get them mixed up (although Jo would probably benefit from a shot of alcohol occasionally to relax and give her relief from the disturbances in her brain).

After a dreadful week of lots of fits and a generally down Jo we prepared to set forth armed with emergency drugs, therapeutic music, familiar pillows, patterns and bed padding. We were putting our family relationships, energy and love to an even greater test and trusting also the patience and understanding of our super kind and mature Esther.

Our Fiat Fiorino converted van piled high with the gear, we set off with an alarmingly composed and alert Johanna (she normally sleeps a lot of the time) looking out at the M6 all the way to Malvern. We arrived at Malvern Wells Youth Hostel, just one step to get the wheelchair and Johanna inside, we were given a good sized 6 bedded ground floor room "as it will suit you better with the wheelchair" they said when I booked - they were right. We ate a hearty supper enjoyed by us all, Jo too, and were joined by two lone hostellers at our table looking for company.

Jo slept soundly in her bunk, we collapsed into ours stunned and relieved - a good start. The next morning we gave her a gastrostomy meal and medication in her bunk at 8 am. We got ourselves ready, cereal and drink for Jo at 10 am and off at 11 am. We were on our way through the splendid Malvern Hills. It was great to be together with no worries about the one we left behind - she was with us.

We arrived at Broadhaven Hostel at 4pm where we were to spend four nights. We had a 5 bedded room purpose built for disabled use which was quite, shall I say, 'cosy', with simple washing facilities and a special high loo that unfortunately Jo cannot use as she is incontinent and wears pads - but we did. Why do people see the disabled simply as those that need high loos?

We were made very welcome by the staff as we were throughout our holiday, everyone keen to help. We 'self catered' and kept Jo's Nutrison drinks in the fridge in the members' kitchen.

Soon we established our morning routine with gastrostomy 'breakfast in bunk' every day. Our first day being fine, we headed for the beach. We had bought a fisherman's tent/beach shelter. We created a bed on the beach, Jo curled into a foetal ball to shut out the world and slept most of the time in an attempt to avoid confronting the elements. Maybe tired from the journey, Jo would not eat or drink so had a gastrostomy meal on the beach. (Is this a first, I ask myself?) Jo does not like bright light, sun, wind, beach - it's all about acknowledging external things. We bring her on holiday in eternal hope that we might have a breakthrough - that we might see a response, that Jo likes the world, that Jo loves us. Not much that happens to Jo physically could possibly cause her to like anything so this holiday is all about hope and a new positive future for her of doing things and being her own person with dignity and respect as a young lady.

Not such a peaceful night - Jo is agitated for whatever reason and we have to sedate her at 6am to give her some rest, and us too. She sleeps on as we have breakfast. In the afternoon we head for Whitesands beach where we picnic in the van, Jo in her wheelchair enjoying sandwiches, salad and thickened juice that we give her on a spoon with regular medication (she cannot drink liquid). Rod and Esther hire wet suits and go body boarding for two hours in the pouring rain, Jo and I sit in the warm dry van, listen to favourite tapes with the rain lashing at the windows.

After another sedated sleep that we all needed, we were all fresh the next day and took off to a stretch on the coastal path adapted for wheelchair use at Druidstone. Feeling the freedom of being in the landscape experiencing the breeze, the smell, the view together, we were intoxicated. It's so good to be away from the crowds, off the road, out of the van. People do look at us as we push Jo, struggling with a heavy wheelchair to get up kerbs, in and out of the van, onto the beach. They look with compassion, pity, maybe with recognition, as we do with others like her, small children puzzled and not able to understand what has happened to this big girl dribbling with a bib on. We are not on some crusade for disabled young people, we are just a family wanting to enjoy the landscape; with not many opportunities to escape and forget that we are different.

One day leads to another, getting Jo washed and dressed, lifting her into the wheelchair, changing her pad with great difficulty in the van. Not to mention the more intimate details and the amazing ability Jo had of adapting. On Wednesday we brave the disabled shower wearing our swimming costumes, Jo enjoys it, sitting on special seat secured with velcro belt from home - a first, an achievement.

On Friday we move on to another hostel, staff amazed at the amount of stuff that we had with us, a lot of it for Jo's care. On to Penycwm Hostel that we researched last year, rural and quiet, beds with sheets - quite luxurious. The two girls had their own room with double and single beds. Jo was the queen spread out in the big bed that she had always wanted. Rod and I next door with intercom from home, to monitor any midnight activities. The hoist that we had hired from the local disabled service centre had been delivered that morning and kindly assembled by the warden. He had previously worked caring for the elderly so know all about hoists. During the whole of our stay he was brilliant and even invited us to a barbecue he prepared for his friends in the grounds.

Jo slept well, with all the fresh air, looking better by the day, enjoying her time out, lazing around, going for walks. Becoming more excited by our outings to the beach, the sun shining, crisp wind blowing, gradually taking surreptitious sidelong glances at it all, there was no way of avoiding what was in her peripheral vision. We had seven very comfortable days, walks collecting mussels on the beach and eathing them later. Jo presiding on the sea wall at Newgale beach on an especially created platform reached by ramp, having a drink in the late afternoon sun, sea sparkling, bathers making their way home past us.

I felt very proud that we were 'out there'.

Written during the bad year 1996 when Johanna frequently required hospital treatment for episodes of Epileptic Status, when we almost got used to the unbearable and did not know where the year would end:

A Voyage of Souls
I would take you on a journey
Show you the world, the sun, the waves,
    the breeze in your face
You would laugh, smile, be at peace,
Belong, be proud. We would belong, be proud.
And everyone would see your beauty.
The sun would have the priviledge
    of shining on your face,
The sea of lapping at your feet.

So we did, and the sun certainly did shine on her face and people saw her beauty. And at the end of each day she returned to the hostel to carry on home routine in a new place with other young people around her to connect with. People were interested, respectful and supportive, and she certainly did belong. We'll be back next year.

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Ethical Issues Surrounding the Use of Observation of Children with Profound and Multiple Learning Difficulties

For all professionals working with children and young people with profound and multiple learning difficulties (PMLD) 'observation' is a vital tool in teaching and in the promotion of learning; the reasons for its use include:

- ***For the assessment of:***
  - -knowledge, understanding and skills in all areas of the curriculum;
  - -ability in all areas of development (physical, emotional, social and cognitive);
  - -approaches to problem solving;
  - -behaviour,
  - -vision;
  - -hearing;
  - -reactions to stimuli;
  - -appropriate rewards (for children who find choice difficult);
  - -methods of communication and interaction;
  - -cultural similarities and differences.

- ***For the monitoring of:***
  - -individual pupil progress;
  - -levels of concentration;
  - -patterns of learning;
  - -mismatch between learning opportunities and the experiences offered;
  - -health problems;
  - -the effects of medication;
  - -the effects of the general classroom environment (especially visual stimuli and noise levels for children with sensory impairments);
  - -the effectiveness of
    - ~ intervention programmes,
    - ~ teaching methods,
    - ~ grouping for learning,
    - ~ equipment & materials.

- ***For the development of:***
  - -whole school policies;
  - -the curriculum;
  - -greater professional competence.

- ***For the evaluation of:***
  - -curriculum content in relation to need;
  - -teaching;
  - -school organisational structures;
  - -policies;
  - -resources.

- ***For general information on:***
  - -how children develop;
  - -friendships;
  - -interests and hobbies;
  - -family relationships;
  - -a greater understanding of a child's point of view.

Tilstone, C. (ed) (1998) *Observing Teaching and Learning: Principles and Practice.* London: David Fulton

But unlike other strategies used for investigation (such as interviewing and the construction and analysis of questionnaires), the ethical issues surrounding the observation of children with or without special educational needs are rarely addressed either in the literature of in practical situations. Owing to their complex needs, the observation of children with PMLD must be as systematic and as accurate as possible and, consequently, in some areas of the curriculum, particularly in personal, social and health education it could be construed as an invasion of privacy. If observation is such a fundamental and important skill, why is so little thought given to its moral implications? And how many schools have policies which consider such issues?

Part of the reason for the lack of such documentation may stem from the loose way in which the term 'observation' is used. The accepted meaning varies in both intensity and complexity and is often dependent on the situation. Sometimes, for example, it is used in relation to casually 'looking' and 'glancing' at children as they are engaged in activities (often in order to *keep an eye open* for emerging problems of behaviour). In other contexts, however, particularly in the intensive teaching of children with complex needs, a level of precision and accuracy is essential and observation can be interpreted as 'scrutinising' and 'investigating'. Whatever the interpretation such observations are intended to lead to informed judgements and to necessary changes in accepted practices. Even glancing and watching may result in the moving or reprimanding of a child with consequent changes to the teaching approaches or to the learning environment. Making predictions which involve change can be interpreted as exercising an element of control over others, particularly when such individuals, by the very nature of their needs, are initially regarded as less powerful. Observation can therefore be interpreted as a means of *surveillance.*

How can teachers find an ethical framework which, on the one hand, does not compromise the importance of the use of observation but, on the other, recognises the need to protect the privacy and psychological well-being of children. I have no easy answers but I would like to consider these issues and would value your comments. As a starting point I will focus upon the rights of the observer and of the observed.

The rights of observers

Observers have, in my opinion, two main basic rights: the right to *know,* and the right to *tell.*

The right to know

Observation is a tool of enquiry which is used within a framework of the development of learning and, in order to promote the learning of each child, a teacher must acquire as much knowledge as possible, and needs to build a comprehensive picture of all aspects of his or her development through the reliable collection of data. For children with PMLD the most reliable method of obtaining data is through the visual evidence of minute changes of behaviour. A range of observational techniques are used (from continuous observation to recording of particular behaviours) all of which require systematic collection, reflection, decision making, and a re-evaluation of the conclusions reached. Systematic observation encourages the categorisation and analysis of data, the re-examination of ideas and the search for a better understanding of pupils within the context of the classroom or school, in order that learning can be improved. Strangely it legitimises the *right to know.*

The right to tell

In addition to the 'right to know' is the 'right to tell'. Jenkins (1986) reminds us that in the interests of children, the teacher must become the 'knower who wants to tell'. He contrasts this position with that of an investigative journalist who is basically a 'teller who wants to know' (p.202). The teacher of children with PMLD is not just governed by the desire to *want* to tell, but rather the *need* to tell in order to ensure that the educational needs of each pupil are identified. Consequently through the shared knowledge of all members of the multidisciplinary team, experiences are extended and learning is facilitated. Rheingold (1982) suggests that in recognising the 'right to know' observers should also accept the *responsibility* to provide reliable data on human behaviour and the process of learning. Vulliamy and Webb (1992) take this point further when they stress that teachers are under an *obligation* to share their findings with colleagues working in the same institution.

The rights of the observed

Alongside the rights of the observer are those of the observed, which include the basic human rights of dignity and respect. In an investigation into the educational experiences of pupils, it is vital that they are not deceived, betrayed or exploited in any way and, as observation can be regarded as *spying,* tact, honesty and sensitivity are essential pre-requisites to the process if such basic rights are not to be violated. However, perhaps the most controversial issues are the right of pupils with PMLD to be protected against intrusion of their privacy and the possibility tat they may be unaware that they are being observed.

These points recognised in the British Psychological Society's *Ethical Principles for Conducting research with Human Participants* (cited in Robson 1993) which states:

> '....particular account should be taken of local cultural values and of the possibility of intruding upon the privacy of individuals who, even while in a normally public space, may believe they are unobserved.'

Teaching is both an art and a science, and as such Webb (1990) stresses the pedagogic research processes involved which, for the teacher of pupils with PMLD, include adopting appropriate methods of enquiry, finding ways of presenting the findings of such enquiries and making sure that they are available to all members of the multidisciplinary team.

The right to privacy

The right to privacy must obviously take into account the settings in which the observation takes place. As Frankfort-Nachmias and Nachmias (1996) remind us, the *home* is considered to be one of the most private settings in our culture, and intrusion into people's homes without their consent is forbidden by law. The extent to which particular settings are public or private is not always self evident and the dilemma may lead to ethical concerns. As a direct result of the attacks in schools in Dunblane and Wolverhampton, public buildings now have severely restricted access. It could be argued, therefore, that such a public setting is in fact private, and that to observe in such a context is an invasion of privacy. What does an invasion of privacy mean in teaching children with PMLD? Are there areas in the school in which it is inappropriate to observe? An initial response for pupils without such complex needs may be 'yes' and toilets and cloakrooms provided as examples. Is it, however, unethical to observe and record the number of times a pupil with PMLD urinates during a determined period of time in order to obtain a 'baseline' for a toileting programme which may ultimately help him or her to become more self sufficient? In this case, the observer's 'right to know' and the benefits that such knowledge affords the children outweigh any suggestion of a breach of their rights to privacy.

The right to be informed

The British Psychological Society also states:

> 'Unless those observed give their consent, to being observed, observational research is only acceptable in situations where those observed would expect to be observed by strangers.' (cited in Robson, 1993 p.474)

As children in school would not expect to be observed by strangers, does such a statement pose an immediate dilemma for the observer? Are legally under-age children, particularly those with profound and multiple learning difficulties, in a position to understand what is involved and therefore is it necessary to obtain their, or (as in the case of video recording and photographing), their parents' consent?

The answers to such questions must surely be influenced by each teacher's responsibility to investigate the best conditions for the promotion of learning, to devise the most desirable teaching strategies for the effective delivery of the curriculum and to contribute to the development of the curriculum itself. Such investigations require children to carry out observable activities (in educational settings) which allow the educational experiences provided by the teacher to be observed through the behaviours of the children themselves.

Although some answers to these dilemmas raised are offered there is a need for all staff in the school to raise their own ethical concerns and to devise their own solutions, which should be documented and recorded.

The need for a whole school policy

By using observation in order to make informed judgements on their practices, teachers and other professionals undertake an inquiry. In other professions inquiries follow strict principles of procedure and rules of practice and, if observation is to be taken seriously as a tool in the teaching and learning process, it should be supported by a policy document, which should be *owned* by all members of the school staff and should reflect their agreed values, the ethos of the school and the nature of the pupils' learning needs.

A suggested framework should include;

- an agreed definition of observation;
- justification for its use;
- the ethical implications agreed by the staff;
- a statement on how observation can be managed;
- the identification of the resources available to carry out observations (the opportunity for 'partnerships' or the use of video recording);
- the in-service requirements of staff;
- information on how the statement will be communicated to parents;
- a description of the ways in which the policy document will be monitored and evaluated, and by whom.

This list is by no means exhaustive and the staff of each school will develop their own headings in order to promote the importance of observation in their own settings. The value of in-school collaboration in the development of a co-ordinated response is a well documented strategy for school improvement (Fullan, 1991; Ainscow 1995, Hopkins, Ainscow and West 1994). Byers and Rose (1996) provide detailed information in four distinct stages on developing and applying policies:

- planning
- formulation
- implementation
- review

The planning stage establishes the purpose of the policy and identifies the professionals who will be most closely associated with its writing. This leads directly to the formulation of the policy itself and on to a consideration of ways in which it can be implemented. In the third stage it will be necessary to ensure that the policy document is implemented and that suggestions are made for any relevant changes. The review stage should ensure that it is developed and extended as necessary. Byers and Rose (1996) remind us that the aim of any policy document is to assist schools to become more effective and consequently 'they should be controlled by the school, and should not be the controlling influence of the school' (p.24).

As a starting point for the production of a policy document, it is often useful for the staff team to agree on a set of principles which will influence both its writing and application. Fletcher and Gordon (1994) record a set of principles, agreed by the staff of one special school, which governed all its work and reflect the basic human rights of respecting pupils'' individuality and privacy.

In conclusion

A serious consideration of observation allows us to learn much from, and about, children. Cohen, Stern and Balaban (1997) remind us that the very nature of each child's ongoing development within the education process implies constant change; that the involved professional needs to be open-minded at all times; and that the skills of systematic observation lead to informed judgements about how a child responds to teaching and learning over a period of time. The education process means that each developing child's *tomorrow* is a little different from that child's *today*, but that the ethical consideration involved in *getting it right* need to be addressed at all times.

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SCHOOLS' LINK PROGRAMMES: AN OPPORTUNITY TO MEET

Children with severe or profound levels of intellectual disability are often excluded from full participation in the mainstream educational system (Jenkinson 1997). Until comparatively recently, there was an assumption that children with the most severe disabilities could only benefit from caring services (Seed 1988). Advances in educational thinking have enabled educators to develop curricula aimed at maximising their potential. It was recognised that education also involved devising programmes to facilitate personal growth and development. A consensus has emerged that priority should be given to developing skills which will enable these young people to function effectively in integrated environments (Helmstetter 1989). In an integrated post-school environment these young people require the ability to socially interact with their non-disabled peers (Evans and Ware 1987). These vital skills can only be learned and successfully generalised through structured daily interactions (Giangreco and Putnam 1991).

Opportunities for young people with severe/profound disabilities to meet and interact with their non-disabled peers are extremely limited. In the Republic of Ireland these difficulties are exacerbated as the vast majority of young people with the severest disabilities do not attend either mainstream or special schools. Alternatively, day services are provided in 'Developmental Day Centres'. Since 1983 a limited teaching service has been available. Almost inevitably the development of educational programmes have been restricted by this type of provision. In addition, the special and mainstream educational systems operated quite independently. Attempts to bridge the parallel systems were confined to sporadic local initiatives. The Fast Friends schools' link programme represented the first systematic approach to developing coherent links between mainstream and special settings.

The Fast Friends programmes originated in two community education initiatives devised by St. Michael's House Research. The CARA Schools Programme provided mainstream pupils with the opportunity to learn about and experience contact with their intellectually disabled counterparts in the local community (McConkey et al. 1983). Project Rally was designed to facilitate increased interaction for young people with the severest disabilities in integrated social activities (Kennedy 1991). A local secondary school, already familiar with the CARA Programme, agreed to participate in Project Rally. Young people with and without disabilities shared curricular experiences in art, crafts and physical education on a regular basis. Structured ongoing contact between both groups was arranged for the whole school year.

A comprehensive study was undertaken to analyse the reactions of mainstream pupils to this type of ongoing contact. It is only possible to give a brief flavour of these reactions within this article. Initially, it was evident that the mainstream pupils experienced a variety of emotions in relation to the prospect of contact. Some pupils felt that they were being offered an opportunity to understand their intellectually disabled peers in a meaningful way as exemplified in the following response:

> *"I think that it's a very good idea because it makes people aware that people with a mental handicap are capeable (sic) of things and that they are just normal people."*

Another pupil expressed a very positive reaction as follows:

> *"I'm glad because I'll learn how to be friends with them and not to be afraid of them."*

Others were not so sure that this was a good idea:

> *"I feel nervous and I feel afraid and I feel unsure about meeting them."*

Positive reactions were evident after a year long period of sustained contact. Mainstream pupils were more confident and assured in their interactions:

> *"I find myself more confident and able to cope with the situations."*
>
> *"I'm not frightened and I'm more comfortable."*

Increased insights into the lives of their intellectually disabled counterparts were also in evidence:

> *"I know now that handicap (sic) people are not people who can't do anything."*

It was apparent that this type of contact represented an enjoyable experience for some pupils:

> *"I've learned how to enjoy a mentally handicapped person's company."*

From this necessarily brief account it can be concluded that mainstream pupils can experience positive interactions with their peers who have the severest disabilities. Confident assurance can replace fear and inadequacy. Enjoyable reciprocal interactions can become the norm. For this to happen mainstream pupils and their counterparts who have the severest disabilities must be afforded ample opportunity to get to know each other in a supportive environment. Overcoming the lack of contact inherent in the present situation represents an urgent task for educators. Creating a society in which young people with the severest disabilities are valued and celebrated must be a priority. Schools' link programmes provide a unique opportunity for young people with and without disabilities to work together on a common project and develop a mutual regard.

Michael Shevlin
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Dublin 2

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McConkey, R., McCormack, B. and Naughton, M. (1983) 'A National Survey of Young People's Perceptions of Mental Handicap.' *Journal of Mental Deficiency Research,* 27, 171-1883

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TACPAC - A tactile approach to sensory awareness

TACPAC brings the skills of a music therapist and special educationalists to the child, young person or adult with profound and multiple learning difficulties (PMLD).

Together they provide a series of movement and sensory activities matched to specific, original music compositions. Three half hour tapes with three matching laminated cards provide all the information a parent, carer or teacher would need to set up tactile activities to encourage early communication. Bobbie Stormont, Hilary Wainer and Christine Marks show how simple household utensils and oddments (such as kitchen sponges, wooden spatulas, yellow dusters) can become the tools for beautiful moments. of contact.

A substantial part of the work done with children and young people with PMLD aims to heighten the levels of awareness and arousal and to promote responses to stimuli. These responses may be reflexive, for example sucking or grasping, Moro (startle) reflex, or they may be perceived as a response to the stimuli.

This activity pack is based on the idea of tactile play, which is an established part of most early years curricula. The skin is the largest sensory organ in the body. It is covered in receptors of varying densities. For the child or young person with PMLD, touch may be the primary means of contact. Such primal responses or behaviours, although perhaps limited in range, are the beginnings of pre-intentional communication. That is, the person does not intend to convey meaning through his/her responses, but the adult interprets these responses as having meaning.

A child or young person showing such responses may be said to be at the pre-intentional reflexive level of communication. Meanings are assigned by the adult to the child's early reflexive behaviours. Meanings assigned are typically like, dislike, want, reject, known and unknown.

TACPAC has an accompanying booklet illustrating the care with which you need to gather the materials and set up an interruption-free and draught-free environment before embarking on the sensitive process of contacting the child or young person who has very little power to communicate. The stereo recordings with Dolby noise reduction invite the teacher, parent or carer to move with appropriate tempos and rhythms for suggested activities.

These would be ideal for a teacher to give to assistants and volunteers to run in their own session as they almost guarantee a consistency of approach. A little training would enable such people to become observant and responsive to the child or young person's reactions and expressions of preference. without this the whole exercise would be entirely passive and the declared intention to communicate would not be fulfilled.

This set is a welcome support to the people who like to introduce musical variations into their activities. The music is specifically composed with orthodox and quirky instrument combinations. They might even encourage people to have a go at providing live accompaniment of their own if extra hands are available.

PMLD children and young people would eventually come to associate particular pieces of music with the activities and sensations and enable them to anticipate events, especially if they were encouraged to feel the materials prior to each section. There are sensible pauses between each piece, and an announcement of what is to come.

TACPAC has been used in William Harvey School, London and if readers would like to find out how they experienced the use of TACPAC, they should contact the Headteacher, Mrs. Margaret Sumner on 0181 808 7120.

TACPAC sells at £30.00 and to order a pact please write to TACPAC, Newdigate House, Church Hill, Harefield, Middlesex UB9 6DX. Please make your cheque out to TACPAC.

The writers would like to acknowledge Robert Orr as extracts from this article are taken from his very favourable review in the RNIB journal.

report back ...

National Focus Group Seminar on Quality of Life Issues

Is your quality of life better than it was six minutes ago? Six hours ago? Six *years* ago? How about tomorrow or next week?

Can you think of anyone whose life you would like to swap with your own?

These were some of the questions asked by Pete Ritchie, Director of Scottish Human Services, at the first seminar of Mencap's National Focus Group in support of individuals with profound intellectual and multiple disabilities (PIMD) held on 18th June 1998.

His questions are difficult enough to answer on your own behalf. How do you begin to answer them for others, including those described as having profound and multiple disabilities?

Pete Ritchie drew a distinction between 'felt states' like joy, being at peace, having a sense of worth and being loved, which are very difficult to score or rank, and comparable external indicators such as life expectancy, safety, freedom from hunger, automnomy and control. Suggestions on how we might judge and measure an individual's quality of life included asking them, trying to put ourselves into their shoes (although this is easier said than done), by observation and by comparison over time.

Judy Cavet, Senior Lecturer at Staffordshire University highlighted some dimensions of quality in learning disability services that in her experience have been prominent in researchers' and providers' minds at different times. These included good physical care, an emphasis on individual development and learning, the provision of an appropriate environment and partnership with users and carers as quality criteria. Others added such things as autonomy, choice and the extent of inclusion and human relationships.

From the parent's perspective Jean Willson spoke powerfully of the importance of having allies for her daughter

> "So for me and mine, even from the grave, I want to have an effect, and we want our lovely daughter's life style to be maintained. All Victoria's life I have worked hard to include others in her life. I know, if left entirely to her staff team, her life would be come very narrow and major decisions would only be made by people who are paid to be with her. She has a circle of friends, trustees and guardians and her life if much richer: she has representatives who know her needs and wishes and these will be safeguarded: they will enable her growth to, as near as possible, complete independence: they will replace me - her champion - they will be there just for her".

Pete Ritchie put forward ten ways in which services can strive for quality of life:

Assume and testify that it matters just as much: validity
There is a danger that individuals with profound and multiple disabilities may not be included because it is sometimes perceived as being harder to achieve, with the associated costs of providing appropriate support. We need to change this culture to finding ways of including people as a matter of right.

Attend to the necessities
There are some absolute necessities for a child/adult with profound and multiple disabilities. Jean Willson highlighted: ***aids, equipment*** and ***transport*** as being key and made a plea to professionals out there:

> "make our lives bearable, these bare necessities must be readily available, repaired, replaced efficiently and effectively".

Find people who can vouch for the person
If someone doesn't have someone to vouch for them, they are unlikely to get what they need.

Value, preserve and enrich family life
Give poeple a sense of a desirable future and look at ways of making it easier for the family to have a positive time together.

Extend social space and nurture uniqueness

Be passionate about communication
Communication is vital. Look for ways of finding out what signs mean in different contexts and act on them. We should avoid having pre-conceived ideas and try to be clear about the judgements we make.

Assume competence and a rich inner life
There was some further discussion on this and it was agreed that there was a need to match communication to the best judgement of the individuals concerned, with staff looking for meaning at all times.

Be warm, be respectful

Make sure that people paid to serve the person like them, treat them well and are interested

Don't segregate or group people on the basis of disability

Quality of life is a complex term and means different things to different people. The group decided that quality of life depended on a number of crucial things including understanding the term; planning for the individual; support and partnerships; positive relationships; effective communication; training for front line staff and a range of quality service provision.

Throughout the day the mportance of relationships for people with profound and multiple disabilities wa highlighted. This challenges us to consider the work we are doing in relation to this - are we focusing on relationships, communication and family life enough?

A full report of the study day is available, and a report of the second Focus Group Seminar help on 12th November on Person Centred Planning will be included in the next issue of PMLD-Link. For further correspondence contact:

Maggie Morgan, National Officer PIMD Section
Mencap, Optimum House, Clippers Quay, Salford Quays, Manchester M5 2XP
Tel: 0161 888 1218
Fax: 0161 888 1211

100 Hours Conference: Opportunity 98

November saw a unique gathering of nearly 150 parents of children with a range of complex disabilities and the care and medical professionals working with their families to discuss ways of better supporting parents.

They were brought together by the charily One Hundred Hours, which works with the families of children with complex needs, in a one-day conference in Birmingham entitled 'Opportunity 98 - real support for parents'.

Dafydd Wigley MP gave the keynote speech, an inspiring talk about his own experiences of having two young children who he lost to a genetic disorder, and how he has used this painful experience in his present work as one of our most energetic campaigners for the rights of people with disabilities. The most useful advice he was ever given, during the time of his younger childrens' illness was to 'take one day at a time'. He also stressed the need of any family in his situation to make use of the benefits available to them. He realises that some may feel they should not take up benefits but stressed this is their right and can ease a traumatic time. He proved himself as not only a friend to the delegates but an understanding, compassionate and active campaigner. He was very reluctant to leave the conference despite urgent businesss at the House of Commons!

A further call to action was given by Philippa Russell OBE, of the Council for Disabled Children. She gave an impassioned plea for those parents who did feel able to speak up for themselves to make use of UK research and international guidance to fight not only for the rights of their children to access appropriate services, their own rights as parents but for the rights of all families with children with disabilities.

As a parent herself she understood the pressures on family life which means that parents are not joining groups as much as they were but stated: 'we have never before had a government with so many agendas for change. It is up to us to ensure that what we want is put into practice.' And she continued: 'Quite properly we put our children first and now our kids are seen as having rights, but it is very easy to forget parents and carers. Parents *can* make a difference. Parents have the power to be innovative.'

She stressed the ethos of partnership between parents and the services available to them but added the proviso that partnership should not mean an escalation of responsibilities, especially when so many parents are already over-burdened.

This indeed, was the message of all the speakers and seminar facilitators - partnership is essential if professionals are to benefit from the expertise of parents when providing appropriate services to families and parents are to ensure they receive the services they need, both for their chilren and for themselves.

The Conference itself was an example of partnership with paired delegates - one professional and one parent - from services throught out the coutry. As Philippa Russell said "the Conference was excellent with a truly inspiring sense of partnership between all concerned. It is so unusual to have more or less equal numbers of parents and professionals." She was not alone in this belief: so many people said how much they appreciated being able to mix on equal terms with parents and professionals from around the country. This feeling was summed up by the words of one statury worker who said she had particularly appreicated "the opportunity to discuss ways of working with parents and workers from other areas."

Professor Hilton Davis from Guy's Hospital spoke with great feeling on the need for professionals to realise that parents are experts - they are undertaking the most important caring role in society. He saw the breakdown of relationships between parents and professionals as being largely the result of flawed communication. Good communication is very difficult to achieve ('just look at the number of divorces and wars?' he quipped) and this is what those in a helping relationship need to achieve. He gave delegates several very convincing examples of how supporting parents with a good communicator simply to listen to them and their needs can not only leave parents feeling much more supported and more able to cope, but also saves precious budgets as they lean less on pressed health visitor and general practitioner services.

Dr. Helen McConachie, Senior Lecturer in Clinical Psychology at the University of Newcastle upon Tyne, summed up the mood of the day in the final plenary. She called for the need for a central base for family services; a keyworker (along the lines of the One Hundren Hours model of support) who could be there for the family and co-ordinate the huge but fragmented input from medical services; adequate training for professionals in supporting parents. This is coupled with need for professionals to work towards quality and sharing information.

A parent from Newcastle stood up and said what many were thinking. She had been asked several times during the day by professionals "where can we find more parents like you?" Her answer was simple. "We are everywhere and we want to help". It is up to services to ask parents for their views and support in inservice development.

Peter Limbrick of One Hundred Hours, chairing the conference, left delegates with a plea that the excellent communication and ideas sharing which had happened during the day should not stop here. We must continue the momentum of the day by keeping up the communication between statutory services, parents and voluntary agencies and work together to achieve services which are both good for the child and supportive of parents, many of whom are currently going through a traumatic time in entire isolation.

A full report of the conference findings will be available from One Hundred Hours in December 1998. The next conference is being planned for September 1999. For details of both please contact:

Gudrun Spencer **Tel: 0121 441 1580**

Moved by Sound: RNIB/BBC Launch of the video SOUND*MOVES*

"Music is a biological puzzle. There is no obvious reason for its existence. But one of its primary functions is to make a whole lot of people feel the same thing at the same time."

Anthony Storr: author of Music and the Mind, commenting on the role of music in the lives of severely disabled children.

A whole lot of people felt the same thing at the same time during the recent launch at the BBC Conference Centre of **SOUND*MOVES*** , a new video which explores the central role occupied by music in the education and social development of children who have severe of profound learning disabilities. The video is a collaboration between the RNIB Education Services and Soundabout, a new national charity which helps staff in special schools to make music with their more profoundly disabled children. The invited audience were emotionally stirred to witness the intense pleasure which music affords even those children who cannot hold instruments, clap their hands or sing. At the other end of the disability spectrum are those young people who cannot read or write or tell left from right, yet who can play complex music on a range of sophisticated instrucments.

SOUND*MOVES* demonstrates how improvised sounds, - and silences - can draw children in a group together, help gain a child's attention through imitation, develop his or her awareness of self and the world beyond, and enable a form of communication which can be more powerful than words. Children are shown enjoying a variety of music devices including ultrasonic beams, resonance boards and everyday sound makers. Sue Lawley provides a crisp voice-over, while Anthony Storr links the children's responses with their very earliest encounters iwth sound in the womb *("Music is enormously physical .. the foetus hears long before it sees...")* with their infantile vocalisations *("I think music probably originated as a form of communication between mother and infant ..")* and above all, with the elation experienced universally in communal music-making.

A range of teachers, trainers, musicians and psychologists discuss the profound effect music can have on the emotions of profoundly disabled children, and explore techniques which enable such children to become more active participants in music sessions.

In addition to **SOUND*MOVES*** and the accompanying booklet **MUSIC MOVES,** the RNIB also launched a resource pack for those working with blind and partially sighted children who have multiple disabilities. Entitled *'Improving Provision for Children with Visual Impairment and Multiple Disability'* the pack comprises three booklets and provides informatin to help ensure that blind and partially sighted children with multiple disabilities have equal access to education.

For more information about the video and resource pack contact RNIB Education, Tel. 0181 968 8600
For more information about SOUNDABOUT ring 01865 876202

A review of SOUNDMOVES and MUSIC MOVES *will be in the next issue of PMLD-Link*

FUTURE FOCUS .... *Music, Movement, and Dance*

In the last three issues of PMLD Link the focus was on important, very serious topics, such as *Quality of Life; The Family; Equal Opportunities and Ethical Issues.* In the next issue we have decided that the focus will be on an equally important though perhaps lighter topic, that of music, movement and dance.

As a non musician, an incompetent dancer and one who rarely moves, I do not feel at all qualified to write this Future Focus. However, I have been collecting material for some time now for background to a publication I am working on related to the creative arts and profound and multiple learning disabilities and this has highlighted for me just how topical this is as a subject for discussiion in PMLD Link.

The wealth of information and innovatory ways of making the creative arts both physically and intellectually accessible for people with PMLD is very encouraging. However, from some written descriptions, it is sometimes a little difficult to separate out theory and philosophy from practice, particularly in a way that others can easily learn from and apply to their own situations. There are some wonderful ideas and examples of adapting and accessing music, movement and dance activities in the many *'Making ... Special'*, and the *'....for All'* publications. What we would like is for you to share and exchange some of your own work and practices in this field with other readers of PMLD Link.

These three activities, music, movement and dance, have many common elements. They can be viewed as being creative, therapeutic, educational and, most importantly, pleasurable. They are powerful means of communication. They may be participated in as a single activity, interlinked or as part of wider arts-based work such as theatre or drama. Most people working in service settings, schools and adult resource services, will be familiar with the work of Veronica Sherborne. She, more than anyone else, has influenced how we encourage children to use and co-ordinate their bodies. Peter (1997) clarifies the distinction between 'dance' and 'movement' as simply , *"dance as being 'movements' combined in a sequence to create a repeatable pattern, often performed to a rhythmic or musical accompaniment"*. This leads nicely into introducing music as an accompainment to dance which is how it is often viewed.

Music is however a very powerful educational tool in its own right. With the new technology such as Soundbeam, Midi, and Midicreator increasingly becoming used in schools, day and leisure settings, its potential is just beginning to be recognised. Soundbeam can be used to create music, encourage movement and as an integral part of a dance programme. Ellis (1995) has developed what he terms 'Incidental Music' as a therapy for children with special needs. Jackson (1995) runs modular courses backed up by detailed course materials on the 'artistry of Sounbeam'. At the Edinburgh Festival this year there was a wonderful show involving people with a range of disabilities, including those with PMLD. This was '*2 days later with Jools Holland: beyond the Edinburgh Fringe*' - it was held two days after the official close of the Festival! In this show, which was not advertised as a 'disability event', the performers, professionals and amateurs, used dance, music and movement very imaginatively. The show was a celebration of the Drake Music Project and the Leonard Cheshire organisation. Such a show would not have been possible without the new music technology that is now at our disposal. Information on this work can be obtained from Janz Duncan at the Drake Music Project in Edinburgh (Tel: 0131 228 5165).

In our multi-cultural society we now have the opportunities to learn from and use the many different dance, music and movement forms. At a conference in Helsinki a few years ago I heard a speaker from India describe how she uses the local dance, the *Tiger Dance,* as the basis for both an educational and therapeutic programme in a centre for children with multiple disabilities. I have recently been sent a videotape of the *Ealing Irish Dancers* a group of dancers with learning disabilities in London, some of whom are wheelchair users, who perform Irish dancing. Anyone who has seen *Riverdance* will know just what an achievement this is - the discipline, movement, music, sheer speed of Irish dancing is not for the faint hearted!

Please do write in with descriptions of how you are working with music, movement and dance. We would like to hear of your successes, and/or details of any forthcoming events you are planning in this areas. Also, let us know if you are encountering any barriers in trying to implement a programme. Perhaps you are having difficulties in either gaining information on new musical technology, access to training, help and support from dancers and musicians.

Loretto Lambe
Projects Director, PAMIS, University of Dundee

References:

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Jackson, D. (1995) *Soundbeam Artistry: A Modular course*: Course Notes. Sandbach: Soundability.

Peter, M. (1997) *Making Dance Special.* London: David Fulton.

Sherborne, V. (1990) *Developmental Movement for Children.* Cambridge: Cambridge University Press.

RESOURCES

NEW BOOKS

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

Communication Before Speech: Development and Assessment (Second Edition)
by Judith Coupe O'Kane and Juliet Goldbart. Published by David Fulton (1998)
ISBN 1-85346-486-4

Innovations in Health Care for People with Intellectual Disabilities edited by Michael Kerr. Published by Lisieux Hall Publications 1998.
ISBN 1-870335-23-6

Innovations in Advocacy and Empowerment for People with Intellectual Disabilities edited by Linda Ward, published by Lisieux Hall Publications

Multisensory Environments by Paul Pagliano. Published by David Fulton.
ISBN 1-85346-553-4

All together: How to create inclusive services for disabled children and their families. A practical handbook for early years workers by Mary Dickins and Judy Denziloe. Available from The National Early Years Network, 77 Holloway Road, London N7 8JZ.
ISBN 1-870985-42-7

The BILD Life Experiences Checklist by Alistair Ager. Published by BILD (1998) and available from BILD Publications Tel. 01752 202333.

Your Good Health - A series of ten illustrated and accessible booklets for people with learning disabilities. Published by BILD and available from BILD Publications Tel. 01752 202333

JOURNALS Etc.

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

COURSES AND CONFERENCES

1999
JANUARY

Date to be confirmed
Sherborne Developmental Movement
Level 2 Course.
Run by: Sherborne Foundation
Venue: Bristol
Further details: Sherborne Foundation
1 The Vale, Pucklechurch, Glos.

18th
Exploring dance and Movement for Fun
A practical day focusing on introducing dance and movement to service users who are visually impaired and have a learning disability.
Run by: RNIB Holiday and Leisure Services
Venue: Edinburgh
Contact: Anne Robson
Further details: RNIB
0171 388 1266

19th
Assessing Communication
Participants will learn how to assess and develop the communication skills of people who are pre-verbal.
Run by: roc training and consultancy
Venue: St. Albans, Herts
Further details: roc training and consultancy
01923 663628

FEBRUARY

9th and 10th
General Sexuality for People with Profound Learning Disabilities
Organised by: CONSENT
Further details: Consent
Woodside Road, Abbots Langley Herts WD5 0HT

10th
Advocating for Health with and for people with learning difficulties
Organised by: The Elfrida Society
Venue: National Institaute of Social Work, London
Speaker: Margaret Flynn
Further details: The Elfrida Society
34 Islington Park Street, London N1 1PX

23rd
Art - The Value of Mark Making
Activities underline the value of the process of mark making rather than the end product. A variety of media will be used including plaster, paint, clay.
Run by: roc training and consultancy
Venue: St. Albans, Herts
Further details: roc training and consultancy
01923 663628

MARCH

8th-9th
Loss and Bereavement
Participants will be encouraged t recognise areas of looss within the livees of people with learning disabilities and explore practical ways of providing support to service users.
Run by: roc training and consultancy
Venue: St. Albans, Herts
Further details: roc training and consultancy
01923 663628

9th Managers' Responsibilities in Supporting Sexuality Work
for Service Managers.
Organised by: CONSENT
Further details: Consent
Woodside Road, Abbots Langley Herts WD5 0HT

17th Supporting Staff Working with Parents on SExuality Issues of Their Son or Daughter
Organised by: CONSENT
Further details: Consent
Woodside Road, Abbots Langley Herts WD5 0HT

17th Post 14 Alternative Accreditation
Organised by: NASEN
Speakers: Judith Wade, Jack Goodfellow, Debbie Bailey
Venue: Nottingham
Further details: Nasen
Tel: 01827 311500

18th-19th An Introduction: Issues relating to Mental Health issues and People with Learning Disabilities.
Introductin to mental health issues and people with learning disabilities.
Run by: roc training and consultancy
Venue: St. Albans, Herts
Further details: roc training and consultancy
01923 663628

19th to 21st A Trio of Opportunities
A weekend on the theme of 'music at the heart of learning for everyone'
for teachers, parents, carers, advisors, therapists, nursery nurses, inspectors care assistants and everyone who is interested.
Choose one of the three courses for your main study and 'dip in'to the others. Some sessions will link all three areas:
Strum as you sing
Musical Interaction
Journey into Literacy
Run by: Special Music Courses
Venue: Nightingale Centre, Great Hucklow, Derbyshire
Course Director: Kate Baxter
Further details: Wendy Prevezer
01155 922 1318

23rd Communication Matters
Conference for all those concerned with supporting people with a learning disability and complex needs; commissioners, purchasers and providers in the statutory and voluntary sectors, including front line workers.
Organised by: Foundation for People with Learning Disabilities and Kings Fund/NDT
Speakers: Jane Jones
Dave Hewett
Venue Mental Health Foundation. London
Contact: Julie Ballard
0171 5

APRIL

9th to 11th Sherborne Developmental Movement
Level 3 - Advanced Practitioners Course
Run by: Sherborne Foundation
Venue: Heathermount School, Ascot, Berks
Further details: Sherborne Foundation
1 The Vale, Pucklechurch, Glos

22nd Challenging Behaviour and Assessment
A National Conference for specialist teachers, Therapists
and educational psychologists working in the fields of visual
and/or hearing impairment/severe learning difficulties
Run by: University of Birmingham
RNIB Education Support Services
Venue: University of Birmingham
Speaker: Professor Jan van Dijk
Further details: Sylvia Franklin-Kitchen
0181 968 8600

JUNE

22nd The NHS - Health for All?
MENCAP/GATEWAYConference to launch
Mencap report. Keynote address by Frank Dobson,
Secretary of State for Health.
Run by: MENCAP
Venue: London
Further details MENCAP
01273 623222

JULY

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: 01908 243619

SEPTEMBER

13th ***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: Westminster, London
Further details: Karen Clarke
Tel: 01562 850251
e-mail: Karen Clarke@bild-edn.domon.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
Furtrher 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

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 thorugh examining the nees 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 disabilties 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

LONGER COURSES (with accreditation)

Interdisciplinary work with People with Profound and Multiple Learning Disabilities
A one year distance education or campus based course for practitioners and carers of children and adults with profound and multiple learning disabilities. The main focus us 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 conjunctin 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 njrses, 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 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

EXBIBITIONS

PLANET display of leisure equipment on the following dates:

24-25 March:	Independent Living South West, Bristol Contact: 01275 ;8;;3;6;465
18-19 April:	Nursery World Under 8's, Manchester Nursery World, 0171 782 3136
28-29 April:	Independent Living Scotland, Glasgow 01275 836465
15-16 Sept:	Independent Living London, Wembley 01275 836465
17-19 Sept:	Nursery World Under 8's, Olympia Nursery World, 0171 782 3136

Further information from Planet, Cambridge House, Cambridge Grove,
London W6 0LE Tel: 0181 741 4119
Fax: 0181 741 4505

18th t0 20th May ***NAIDEX*** International Exhiition
Venue: NEC Birmingham
Further details: Reed Exhibition Companies
Tel> 0171 910 78873

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.

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