PMLD LINK

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In the last issue of **PMLD Link**, Carol Ouvry reported that the members of the Editorial Board - grand title for a small working committee - would take it in turn to write the Newsletter's front page. It is my turn this issue.

We were pleased with the response to our request for information and articles from people working with adults with profound and multiple disabilities, please keep up the trend. Throughout the country services for adults in general but for those with this degree of disability in particular are not good. We would be very interested to learn of any innovatory provision you may be aware of, or indeed, involved with. Pleease do send in details as the only way to spread the word about good practice is through free exchange of information. In this issue, James Hogg describes plans for a day service for adults being developed in Dundee, Scotland, by a parent led voluntary organisation, the statutory services and a University research department.

Throughout the country problems are still being encountered in relation to the statementing procedure. Lord Campbell of Alloway's Private Members' Bill, amending the **1981 Education Act**, recently received its Second Reading in the Lords. This Bill draws attention to the difficulties related to the statementing procedure. The aim of the Bill is to speed up the process of statementing children with special educational needs and to improve the appeal procedure relating to statements. Daffyd Wigley MP intends tabling amendments to this Bill when it reaches the Commons, asking that an <u>independent</u> panel to deal with statementing be established, or, if this is not acceptable, then at least the review panel should consist of members independent of the local authority. This will be a very important piece of legislation if it reaches the Statute Book and readers will be aware of cases that could be used in the campaign to improve the statementing procedure. Ann Watson, Parliamentary Affairs Officer, Mencap, would welcome hearing from you of any such cases. Her address is: Mencap, 123 Golden Lane, London ECY ORT, Telephone: 071 454 0454.

Ann has responded to my request to draw attention to the importance of legislation in the field of learning disabilities by writing a short article for this issue of **PMLD Link.**

Advocacy as a movement is spreading in the UK and again we would be interested to hear of advocacy schemes for people with profound and multiple disabilities with which you are involved or may know about. I have recently been commissioned to carry out a feasibility study on the needs for advocates for residents of a long stay hospital and in relation to this I am reviewing the literature on Advocacy. Any references or contacts on the topic of advocacy would be most welcome. In a later issue of PMLD Link I will report further on the study.

Integration, or more correctly, inclusive education, has been debated fairly widely of late, see the item by Helen Mount on the 'Great Integration Debate Conference' held in Manchester in early May. This topic will, over the next year or so, continue to task our minds. Everyone involved in services for people with disabilities must in principle support integration. What we must never accept, however, is lip-service to integration. We must all strive for better services and improved quality of life for people with profound and multiple disabilities not follow trends for the sake of them. We would welcome readers views on this issue.

Reading through past copies of the Newsletter I notice that Carol usually ends with two reminders so I will keep up the tradition. First, a gentle reminder to those readers who have not yet paid their annual subscription. There is a subscription form at the back of this issue. If you do not require it to renew your own subscription please pass it on to a friend or colleague. Second, please do continue to send in articles, information, letters,and please note that items for the next issue should be sent in by the end of October 1992. Finally, for those readers lucky enough to be planning holidays, have a well earned rest and happy holiday.

Loretto Lambe

June 1992

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The White Top Centre, Dundee

While school provision for people with profound learning disabilities and multiple impairments has improved dramatically over the past 10 years, services for this group on leaving school are often woefully inadequate. Day service provision may be entirely lacking, or of such poor quality that parents and carers reject what is on offer.

Tayside Regional Council Social Work Department has been committed to improving this state of affairs, and already good provision will be found in Arbroath and Perth. There has been a widely acknowledged need for similar services in Dundee, and the development of the White Top Centre has been set in motion following preliminary research by Dr Philip Seed of the University's Social Work Department. Dr Seed identified a number of adults with profound and multiple disabilities in the City who required good quality day and short-term respite services.

This work led to a decision to establish just such a service. The White Top Foundation, which supported the research, is funding the building of a purpose-designed facility on Perth Road, Dundee, with additional support from the Gannochy Trust. Tayside Regional Council will be responsible for running and resourcing the Centre, with a considerable therapeutic and nursing input from Tayside Health Board. The Centre will open some time in 1993.

The young men and women who will come to the Centre all have profound learning disability and physical and/or sensory impairments. There is no upper age limit for those attending, though this initial group are between 18 and 35 years. While provision will be made for 15 people at the outset, it is hoped that the White Top service will benefit a larger number of people with profound and multiple disabilities through assessment and advisory procedures.

Staff will include skills tutors, drawn from diverse backgrounds in the field of education, training and the arts, a bio-engineer, a development officer, residential officers, physio, speech and occupational therapists, specialist nurses, as well as number of other training, care and support staff.

The White Top Centre will offer a comprehensive, interdisciplinary service, with a strong emphasis on involvement in the wider community. The Centre will act as a resource centre for others working in this field, offering training, assessment and advice within the Region and more widely.

The Centre's Director, Professor James Hogg, holds a dual appointment, employed by the University, but also responsible to the Director of Social Work for the running of the White Top Centre. A "White Top Research Unit" is being established within the University to undertake work on profound disability. The research itself will be carried out partly in the White Top Centre, but also more widely in the Region in collaboration with both the statutory and voluntary sectors. Funding for the Unit's research is being sought from many sources, with successful bids already having been made to the Scottish Office Home and Health Department and the Scottish Council for Spastics.

For further information, contact Professor James Hogg, The White Top Centre, Department of Social Work, Frankland Building, The University, Dundee DD1 4HN.

James Hogg

13 May 1992

IT'S ALL WHITE NOW!

At Blackmarston School, a primary school for pupils with severe learning difficulties, we set up a white room about 18 months ago. Initially we had experimented with a darkened room and some torches, none of which were very satisfactory. We had a small disused time out room which was a very simple construction of plywood, and not sound-proofed. One of the parents doubled the size of it which cost about 100. A community service volunteer painted it all white.

In order to obtain the right equipment we had a representative from a company to give a demonstration of various items. We made a list of requirements which amounted to a bill of around 2,500. The money for these items came from a charity. Most of the equipment is relatively hi-tech, but by no means all of it. Some lo-tech equipment such as fairy lights and fibre optic wands (1.50) are just as effective.

We found it fairly easy to obtain the equipment, but by far the most difficult thing is to use the equipment in a consistent and effective manner. In order to achieve this the white room is heavily timetabled out, and a record sheet has been developed (see fig.1) to monitor the responses of pupils to various sources of stimulation. Figure 1 shows an observation sheet on which are marked the responses of pupils to various stimuli. The sheet is based on the Affective Communication Assessment (A.C.A.), produced by Judith Coupe and Linda Barton.

We have produced some guidelines for staff using the white room. Staff are encouraged to give themselves and the pupils time to relax on entering the room and then time for each stimulus to be registered. Time is allowed between each stimulus so that a pupils is not bombarded. Only one or two pieces of equipment are used for each session. It is important tht the time spent in the white room is the optimum time for the child, for exammple not when a child is 'switched off' or sleepy.

The white room equipment operates on two levels. The first is a passive one whereby a pupil may be stimulated and evidence of tracking or reaching out may be observaved. The second one is an active one whereby a pupil starts to control his environment through a variety of switches. This conceptual leap of cause and effect is an extremely important one.

It is mainly children who have profound and multiple learning difficulties who use the white room facilities, but it does have a secondary role with some other pupils who find it motivating and are encouraged to communicate and to make choices.

It is important to use the white room as part of the curriculum. All pupils have termly forecaasts and, where appropriate, the white room experiences will be drawn into this. Without this systematic planning, and purposeful use, it is easy for the sessions to become novelty experiences without any real purpose of function. It also helps to prevent it from being the next fashionable innovation. Used appropriately a white room can be of value to the curriculum offered to pupils with profound and multiple learning difficulties.

Frank Price - Headteacher of Blackmarston School, Hereford

Child's Name ____________________

Adult's Name ____________________

Recorder ____________________

		STIMULUS + DATE			
FACE	FROWN SMILE NEUTRAL ANY OTHER COMMENTS				
EYES	LOOK SEARCH FOLLOW ANY OTHER COMMENTS				
HANDS/ ARMS	ACTIVITY REACH CONTACT ANY OTHER COMMENTS				
BODY ACTIVITY ANY OTHER COMMENTS					
VOCALIZATION	UTTERANCE CRY LAUGH ANY OTHER COMMENTS				
OVERALL IMPRESSION					

ParliamentaryAffairs

Parliamentary affairs,MPs and Government can seem very remote from our daily lives, but they are important.

Discussions, debates and decisions are happening every day which have direct impact on the future of people with profound intellectual and multiple disabilities.

The role of Parliamentary Affairs, at MENCAP National Centre, is to monitor and participate in these debates, and influence the decisions being taken. This cannot be done without information on what is happening in the real world. If there are problems, then we need to let the politicians and civil servants know what those problems are, and suggest solutions. **If we do not protest, then nothing will change.**

Do you know of any problems; for example: lack of appropriate respite care; lack of support for families; problems with disability benefits; lack of opportunities for care not being properly funded; and of course, problems related to the statementing process ? How will individuals you know be affected? Let me know and we will make sure that Government knows.

From time-to-time I will do a brief up date for **PMLD Link** on Parliamentary Affairs, covering changes in legislation and how this will affect people with profound and multiple disabilities. If you have any queries related to campaigning or parliamentary matters please to get in touch.

Contact me at the address below or ring me on **071 454 0354**

Ann Watson
Parliamentary Officer
Mencap
123 Golden Lane
London EC1Y ORT

The Mencap Profound Intellectual and Multiple Disabilities Section (PIMD)
Piper Hill School, 200 Yew Tree Lane, Northenden, Manchester M23 OFF

The Mencap Profound Intellectual and Multiple Disabilities Section (formerly PRMH Project) is a national Mencap initiative based in Manchester. It was established in January 1985 as a result of direct pressure from parents who wished to see a more positive input for families and other carers providing for both children and adults in this group.

There is a core of three staff led by Helen Mount, the Co-ordinator, and an Administrator and Information Officer. Professor James Hogg of the University of Dundee acts as Consultant and assists in evaluating various aspects of the Section's work.

The Section has three major aims:

i) to establish the needs of people with profound intellectual and multiple disabilities and the related needs of their parents and carers through a detailed national survey

ii) to develop training models offering guidance to parents, professionals and carers in areas where assistance is required (as identified in the survey)

iii) to act as a 'national information resource' for parents and professionals concerned with people with profound and multiple disabilities

The results of the national survey, undertaken in the mid 1980's, highlighted seven priority areas viewed by parents and carers as those in which training would be helpful. These were:

- Communication and Feeding
- Physical Management
- Management of Difficult Behaviours
- Dental Care and Diet
- Planning for the Future
- Leisure Opportunities
- Rights and Entitlements (Understanding Benefits and Allowances)

Each workshop was run twice (Pilot and Phase 2) and fully evaluated each time. Evaluation Reports on each of the topics are available from the PIMD Section at a cost of £2.50 per copy (incl P&P).

DISSEMINATION OF WORKSHOP MODEL

For each workshop, the course tutor provided information and resources which are currently being used to develop training packages on each topic. The training packages when completed will comprise a tutor's manual, an administrator's manual, and participants' manuals. It is intended that these training packages will enable interested professionals from different disciplines to organise workshops in their own area and thus disseminate the information nationally. PIMD Section staff will provide management support and advice in putting on workshops. the first training package is due for publication in December 1992, and the remaining topics will follow at three monthly intervals.

LEISURE SCHEMES:

For some years, in response to local demands, the Section has established and run a number of leisure schemes and initiatives for children and adults with profound intellectual and multiple disabilities. These are fully described in available reports (Lambe 1986: Lambe and Barrett 1988). Because it is essential that parents attending workshops have respite from caring for their son or daughter, it has proved possible to conduct workshops in the same locations as the leisure schemes, allowing sons and daughters to receive leisure provision while mother, father or carer attends the workshop. This arrangement has the additional advantage that the son or daughter can be involved in the workshop as and when required.

LEISURE RESOURCE TRAINING PACK:

The PIMD Section in conjunction with the National Federation of Gateway Clubs and Hester Adrian Research Centre in Manchester has published a Leisure Resource Training Pack for use by volunteers, professionals, parents\carers and anyone else attempting to provide leisure opportunities for people with multiple disabilities.

The booklets in the pack cover a wide range of issues, ranging from care of the person with disabilities to discussions of specific leisure activities. There is also a video and a comprehensive resource directory of useful organisations and distributors to contact.

The materials were piloted in the Manchester area and also in Northern Ireland, prior to the pack being published. Publication charges have been underwritten so that the pack is available at production costs in order to widen its dissemination.

The PIMD Section Co-ordinator and Gateway's National Training Officer, are currently organising a series of conferences about the pack and anyone interested should contact the PIMD Section.

DEVELOPMENT OF INFORMATION RESOURCE

Information on all aspects of provision for people with multiple impairments has been collected and is shortly to be computerised. The Section responds to requests for information from both parents and professionals, not only from the UK, but also from Europe, the USA, Australia and developing countries. As part of this information-gathering, a small library of books and video tapes has been assembled. Information sheets on different topics, e.g. selected references and specialist suppliers of equipment etc., has been drawn up by the Section team. Details of other specific projects or initiatives related to people with multiple handicaps would be welcome by the project.

FUTURE DEVELOPMENT IN WORK WITH PEOPLE WITH MULTIPLE DISABILITIES

The PIMD Section initiative has demonstrated the massive need parents and carers have for information and practical guidance. It has also shown that assistance can be given leading to the alleviation of their difficulties and to improvements in the quality of the lives of their sons, daughters and clients.

For further information please contact:

The Mencap Profound Intellectual & Multiple Disabilities Section
Piper Hill School
200 Yew Tree Lane
Northenden
Manchester M23 OFF
Tel: 061 998 4161

INTERDISCIPLINARY WORK WITH PEOPLE WITH PROFOUND AND MULTIPLE LEARNING DISABILITIES

The University of Birmingham and BIMH are collaborating to respond to a perceived need for training for staff who are working with people with pmld. There are very few courses available and even fewer that offer the chance for accreditation. (Qualified teachers can study for an Advanced Certificate in Education and other staff for a BIMH Certificate in Disability Studies.)

One of the acknowledged difficulties that arises when working with people with pmld is that of making sense of the different priorities identified by the many professionals who work in the schools, hospitals and day centres. At the heart of the new course is the notion of collaboration, to the extent that course participants are encouraged to bring with them, a colleague with whom they work. If this is not possible, then there should be a strong commitment to work with a colleague/s at the place of work on the practical activities and assignments set as part of the course.

Running a course in this manner is undoubtedly innovative and the success of the formula has yet to be evaluated. However, it is very encouraging to meet with extremely positive comments when the principle of collaboration is discussed with staff who work with people with pmld. There are many genuine teams of professionals attempting to work together against enormous difficulties presented by lack of time and resources and the frustration of enormous case loads and poor management.

The course "Interdiscipliary work with people with pmld" will be run at the University of Birmingham on Thursday evenings over a year during University terms. It consists of three modules, the first of which is an introduction which aims to help course participants to develop a greater understanding of the nature of pmld in the light of changing social attitudes and current service provision. The second module builds on this and a range of interventions for meeting the needs of people with pmld is explored and discussed. The final module concentrates on assessment and evaluation and also gives students the opportunity to consider how to affect change in their own institutions.

There are two themes running through the modules. The first is collaboration between professionals, perhaps from different disciplines, and this has already been highlighted. The second is the importance of the development of communication and social interaction in the lives of people with pmld. Course participants are encouraged to study pre-verbal communication and the ways in which carers can respond to people who are at this developmental stage. Alternative forms of communication are examined as are strategies for encouraging speech and language in a variety of contexts.

The first run of this course begins in September 1992. It is a very exciting venture, especially as there will be a course team of eleven people from a variety of disciplines! Trying to co-ordinate all that expertise and experience will be a challenge but it is one we are looking forward to with great enthuiasm. Next year, it is hoped that the course will be available as a distance learning package so that people who do not live close to Birmingham can be involved as well.

If you want to know more about the course please ring:

Penny Lacey (Course Co-ordinator) at the University of Birmingham
021-414-4878.

PRE-INTENTIONAL COMMUNICATION
A PRACTICAL LOOK AT THE AFFECTIVE COMMUNICATION ASSESSMENT METHOD

A colleague and I worked together with a child called Jenny, a three year old with profound and multiple learning difficulties. She was born with a Dandy Walker cyst, causing hydrocephalus. This was treated surgically with a shunt. She is described as having Spastic Quadriplegia; she is epileptic and registered as cortically blind. She has recently undergone a hip operation and understandably is somewhat averse to being held. Much of the work done with her took place with her sitting in her pushchair. Jenny is non-ambulant and her limb, head and body movements appeared to be involuntary. Jenny is part of a class of children all of whom would be described as having profound and multiple learning difficulties (PMLD).

The aim in the time planned with Jenny was to use an "assessment of existing behaviour and responses" (DES,1975) to plan for future development and hopefully to begin a programme of intervention, the purpose of which would be to encourage the development of affective communication. Both Piaget (1952) and Vygotsky (1978) have shown that development occurs via the interaction that an individual has with his/her social and physical environment. "The environment influences the child, but also the child's behaviour influences the environment, which in turn influences the child and so on." (Glenn, 1987 and Hogg and Sebba, 1986) It is as the child becomes aware that his behaviour has an effect on his environment that intention develops. For the realization of the child's intentions, Halliday (1973) sees "language" as "a rich and adaptable instrument" (as quoted in Hogg and Sebba, 1986) For a child like Jenny, spoken language may always remain a closed door, but language in the wider sense of communication and intentional interaction should hopefully, if only in a very limited way, be within her grasp. That this ability to communicate should be achieved for her and others like her is of "prime importance in the curriculum." (Ouvry, 1987.)

Ouvry describes this early stage of pre-verbal communication as

> "the stage in which the interactive patterns and underlying cognitive processes are established, in preparation for the use of more complex receptive and expressive systems involving the use of established conventions and orthodox systems" (Ouvry, 1987)

Ouvry also points out that for some children any early interactive exchanges that are established may remain their only channel of communication.

We come on now to the practical work that was to be done with Jenny, assessing her present development and planning the appropriate intervention. In this, the method described in "Affective Communication" by Coupe, Barber and Murphy. (1988) was followed. Jenny was given sensory stimuli and her reactions recorded and "interpreted." It was found that Jenny, like the little girl in Coupe, Barber and Murphy's study, was also functioning at a stage of pre-intentional communication. At this stage it is we who interpret the responses and place meaning on them. Her reactions are to the stimuli themselves, but it is "possible for us to interpret these responses and place accurate communicative meaning on them." (Coupe, Barber and Murphy, 1988) It is necessary to recognize and record any consistent responses to the child's feelings of like and dislike, want or reject. "Consistent repertoires of behaviour" can then be identified and used to draw up "specific programmes of intervention".(ibid) The initial assessment was carried out with Jenny, using the Affective Communication Assessment Observation Sheet. To the stimuli presented, Jenny's responses were mostly positive or neutral; in fact on that first occasion there was nothing that brought about a definite dislike reaction, except perhaps a drink of water, offered in a feeding bottle. Salad cream was offered and the initial, nose-wrinkling reaction might have been interpreted as dislike, until it was offered a second time, when Jenny opened her mouth, smacked her tongue and blew bubbles, following this with a vocalisation, classed as a "gurgle." The nose-wrinkling was then interpreted as Jenny's response to something new or strange. Jenny seemed to enjoy most of the stimuli to different degrees, perhaps appreciating the social interaction as much as the stimuli themselves.

Having made the initial assessment with the ACA Observation sheet, on the next occasion, we went on to use the ACA Identification recording sheet. With this, Jenny's most regular responses were listed and these were monitored in a further session and checked for consistency. It had been noted that with the presentation of each stimulus, Jenny's head and whole body would still. On checking this, it was found that this happened particularly with stimuli which Jenny appeared to find pleasurable, whereas when offered playdough to feel, or when taken out of the push-chair, this stilling did not occur. The lack of stillness along with the nose-wrinkle would seem to indicate mild dislike, although the nose-wrinkle continued sometimes to indicate a reaction to something new or strange. .To a stimulus that Jenny "liked" she would smile, although it was noted that for this response, and for most others, we would have to wait about ten seconds. The aim at this stage was to intervene in order to establish responses which could appropriately be interpreted and encouraged to indicate like and dislike, want and reject. Jones (1989) refers to this as "Idiosyncratic Non Verbal Communication," because the student's ways of indicating likes, dislikes and basic needs may be highly individual. For "like" a smile was Jenny's fairly consistent response, and for dislike the nose-wrinkle, (remembering to check again to ascertain that it was not just a "something-strange" reaction) turning away the head and an occasional cry were her indicators.

Looking for a response to indicate "want" or "more" was not so straightforward. Jenny did not appear to have developed any means as yet of communicating "want," yet this would be a meaningful step forward for her. As Ouvry says,

> "By repeating certain behaviours children gain expected responses and, once they have learned this, they can deliberately influence the course of their interactions."
> (Ouvry, 1987)

Jenny often blew bubbles or 'raspberries' after something she had enjoyed, although this may well be a form of self-stimulation along with her finger and hand sucking. She consistently stilled for a stimulus, but this did not seem to be a pronounced enough indicator to use for "more".

It had also been noticed that on occasions. Jenny would raise her arm, and rub her head with the back of her hand. This was not apparently in response to anything in particular, but it seemed to us that as she had the motor skill to perform this action, it would be worth trying to target this action as an appropriate way to communicate her desire for "more" or "want." Certainly it would seem more socially acceptable to indicate her preferences in this way than by going through life blowing raspberries to ask for something!

Having made this the objective, on the following session with Jenny, time was first spent checking some of the known responses with known and fresh stimuli. After some short time of offering stimuli, Jenny rubbed her head following the squeaking of a toy. "Do you want more?" we immediately asked and repeated the squeak, aiming to link the idea of "more" with the head rubbing. Later, a tiny piece of chocolate was offered to Jenny. Jenny kept the chocolate in her mouth, chewing it after a while, and then when it had all gone, she smiled her pleasure. She was then asked, "More, Jenny?" and her hand was lifted and a physical prompt given to rub her head. Immediately another tiny piece of chocolate was popped into her mouth. This time when it had all gone, we waited and several seconds later, she slowly lifted her hand and rubbed her head! Cunningham has said that "educators of the profoundly mentally handicapped must find excitement in the process of teaching, rather than in results." (Quoted in Bailey, undated) As we had been working, we had been experiencing this excitement in the "process," but what a bonus it was to have a "result!"

Was this just a coincidental response, or was Jenny at the right moment to learn that a response which hitherto had been non-intentional could be used in intentional communication? The test would surely be in whether this response would be maintained and generalised. Jenny continued to rub her head after finishing each little piece of chocolate, but would this response also work with other stimuli? When she had finished one piece of chocolate, but before she had time to rub her head, we presented another stimulus, this time the sqeaky toy sound which she had enjoyed previously. Twice a physical prompt was used, lifting her hand to rub her head, while saying, "More, Jenny?" and then the third time Jenny rubbed her head voluntarily! Various other stimuli were tried, including sounds, blowing on her face and a drink. With each, after a number of physical prompts, varying from one to three, Jenny rubbed her head, indicating "more" for herself.

Perhaps the biggest indicator that these were not haphazard or coincidental responses was what occured after we returned Jenny to the classroom. The other children were having their drinks, so Jenny was given a bottle of tea. She is encouraged to have her drink held/propped in her hands while drinking. After a while the bottle slipped from her hands, and a few seconds later she was noticed to be rubbing her head!

The class teacher when informed of the progress was enthusiastic to continue reinforcing this reponse, and also was going to inform Jenny's mother so that she could follow up at home.

Vygotsky stresses the significance of assisted performance. His concept of the "zone of proximal development as being the "distance between the actual development level as determined by individual problem solving and the level of potential development as determined through problem solving through adult guidance" (Vygotsky, 1978, as quoted in Light et al 1991) was well illustrated through our experience with Jenny. Vygotsky talks of those functions that have "not yet matured but are in the process of maturation, functions that will mature tomorrow but are currently in an embryonic state."(ibid) We felt that we had been privileged to be a part of one of Jenny's "tomorrows"!

Having worked so far with Jenny, the next step would be to plan future intervention and develop strategies to reinforce and extend the progress made. An important aspect here would be to continue to work with Jenny in a social, interactive setting. As Schaffer (1986) asserts,

> "Cognitive functions require a social context for their initial emergence and subsequent facilitation before they eventually become internalised as properties of individuals." (Schaffer, 1986, as quoted in McConkey, 1987)

Ways should now be sought in which Jenny could learn to control her own environment. Not only could she ask for "more," but the next step might be to encourage her to indicate a requirement for a need, not already being met. If she were hungry, thirsty, etc., a response could be encouraged to mean, "I would like." From here hopefully she could be taught how to indicate what she needed at that moment.

Another area which I would see as a future priority with Jenny would be that of vocalisation. At present Jenny's vocalisations are restricted to sighs, crying, very occasional chuckles and even rarer gurgles. As Bloom (1978, in Cooke and Williams, 1985) indicated, vocalising for the younger child is not purposeful, but a reflex action, reflecting feelings of hunger, discomfort and pleasure. Thus, for vocalisation as for other responses the child with learning difficulties needs to be taught intentionality. Once vocalisation were established with Jenny the aim would be to make this meaningful, by helping her to use sounds to indicate her wants, in much the same way as she was encouraged to rub her head for "more."

That Jenny's handicaps are profound cannot be denied, but we were greatly encouraged in the time we spent with her, seeing what we, perhaps naively, classed as progress. We had found the Affective Communication Assessment to be an extremely useful tool in our task to assess, plan and begin an intervention. In ordinary, every-day observation, it is easy to miss small indicators and even to misinterpret levels of response. In this respect also, we found how invaluable it was to be working in a pair. Our experience proved that alone it would have been impossible to present stimuli, observe, and record responses all at the same time! Using the ACA helped us to target and pinpoint responses which could otherwise have been overlooked. With the child who has profound and multiple learning difficulties, there is so very little response to work with that it is of paramount importance to ensure that not even the tiniest opportunity to promote communication is lost. Coupe, Barber and Murphy rightly refer to the "wealth of information" which can be gathered from using the ACA and from which "the adult can make predictions regarding the child's repertoire of affective communication and plan appropriate programmes of intervention." (Coupe, Barber and Murphy,1988)

Celia J I Foote 1992
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CJIFoote

AN OBSERVATION INTO THE ORGANISATION OF A SPECIAL NEEDS UNIT IN ORDER TO CLARIFY THE TIME SPENT ON TASK BY INDIVIDUAL CHILDREN.

Old Park is a school for children with Severe Learning Difficulties.It has 107 pupils on role between the ages of three years and nineteen years, and a staffing establishment of 14.5 teachers and 14 Special School Assistants.(S.S.A.) It is organised into three Phases based on National Curriculum Year groups. These are managed by Co-ordinators with responsibilities for Early Years ,Middle Years, and Upper Years. Special Needs,Class 9 ,being all age range,has the involvement of all three Co-ordinators. The Deputy,as curriculum manager,has an overseeing role. The Phase Co-ordinators,the Deputy and the Headteacher form the Senior Management Team.(S.M.T.)

The need to restructure Class 9,a group of children with Profound Multiple Learning Difficulties,had been highlighted in the School Development Plan. Changes in pupil numbers and severity of handicap had altered the composition of the class, creating difficulties in classroom management and organisation which reflected in the time pupils were on task. Staff morale was low,and in an environment where progress is slow,and responsiveness limited,it was crucial that motivation be maintained.

Recognising the limitations of their own experience,the S.M.T.considered that without first hand knowledge of the management and organisational issues,presented by a group of profoundly handicapped youngsters, meaningful decisions could not be made.

The class has a full time teacher and three S.S.A.'s, a fourth S.S.A. is based with the group for 85% of the time,the remaining 15%,she is based elsewhere.

Of the eight children observed,from a class of fourteen, two were mobile,six were immobile.One child was deaf,blind,immobile and non responsive,another partially sighted.Four of the group were capable of indicating awareness of surroundings,with an ability to indicate recognition and to differentiate between persons. All are totally dependent for all functional skills.For all activities it is necessary to physically position them.

Time on task was seen to mean that period when a child was working one to one with either an S.S.A. or Teacher.The position of the child could be solitary or as part of a group. It was not intended to count periods of self occupation as time on task.

Four one hour sessions were observed daily for four days.Observers were paired as it was decided that post observation discussion would be more meaningful as a shared experience. Observation procedures were defined to reduce individual opinion. At five minute intervals notes were made on what the child was doing. Other observations on what staff were doing,the management of materials and equipment and the placement of children were also made.

At the end of the four days a matrix, was completed which illustrated that there was inequality of time between children,and that a large proportion of time was spent off task rather than on. Diagram 1 illustrates the mean average of time on task per hour per child. Over the four hour period the time on task per child ranged from 22.75% to 41.65%.

NAME	HR1 ON%	HR2 ON%	HR3 ON%	HR4 ON%	AV.DAY TIME ON
W	25%	25%	16%	25%	22.75%
I	0%	25%	41.6%	33.3%	24.97%
K	33.3%	33.3%	33.3%	16%	28.97%
M	50%	41.6%	16%	25%	33.15%
J	33.3%	25%	50%	41.6%	37.47%
N	41.6%	25%	50%	41.6%	39.55%
S	41.6%	33.3%	50%	33.3%	39.55%
JB	50%	25%	41.6%	50%	41.65%
AVERAGE/HR. TIME ON	34.35%	29.15%	37.313%	31.15%	

DIAGRAM 1

The results for the first hour illustrated that 24% of the group had 50% time on task,25% had 41.6%,25% had 33.3%,13% had 25% and 13% had 0% contact.It also illustrated that 25% of the children had 50% time on task.The two least responsive had the least time.

The second hour resulted in an increase in the time off task. Some 62% of the pupils had only 25% time on task which is five out of eight children.Only three had more time on and this was less than the time for the first hour where six children,(74%),had between 33.3% and 50% time on task.The increase was towards the least responsive.

Hour 3 illustrated that 74% of children had between 33.3% and 50% time on task.A reflection of Hour 1 in terms of percentage.The time for individual children was about the same with the same responsive four having the most time. It was noted that Child W still only had 16% of time on task.This child was the least responsive.

The final hour still had a range from 16% to 50% time on task with the three most responsive children receiving between 33.3% and 50% time on task.This Hour unlike Hour 2 had it's period of inactivity at the beginning of the session rather than towards the end.In all cases the most responsive had the most time on task.

Observation of the group illustrates that long periods are spent off task.Remembering that on each day only two were being observed,it would be incorrect to state that this is the result of staff not being actively engaged.While the teacher was not engaged with the child under observation she would be engaged with another. The results give cause for concern. The percentage of off task range from 77.25& to

58.35%.What should concern the practitioner is that between 60% and 70% of time is spent not on task per hour and between 58% and 76% per day. All but one child,JB,spends on average less than 40% of time per day on task.This means that 1hour and 38 minutes is spent on task in a four hour period by JB while child W spends only 52 minutes on task for the same period.This variation between children is also a concern.In the first hour the range is from 0% to 50%.What does become clear is the more responsive the child the the more consistant the time on.Not one of the top four responsive children had less than 25% time per hour.

General classroom observation produced several facts. One considered to be important was the positioning of children. Staff spent a considerable proportion of time moving children from one place to another just to carry out an activity.This made an impact on the time children spent on task.In some cases more time was spent moving the child than actually working with him.

Time was also spent positioning children for a work activity and every time the child or the group were approached a member of staff would slightly alter the position of a child or a piece of equipment.

The staff also felt the need to keep the children constantly occupied with some activity or other.In discussion it was clear that their perception was that the children should be occupied at all times.An example of this was breaktimes.Instead of grouping children and allowing them the opportunity to opt out once they had had a drink,the staff immediatly found something to keep the child occupied.eg.a mirror placed in front or crinkly paper under foot or on a lap.

The findings clearly illustrated that time on task was related to the responsiveness of children.This in turn affected staff motivation and satisfaction. The greater the response from the child the more staff are motivated. It also found that time on task diminished as sessions progressed.Fresh input from staff after a period away from the group occurred.It also emphasised that a heirarchy was created based on childrens responsiveness.

As an example, child W is the most handicapped of the group being blind,immobile,non responsive to external stimuli, with staff struggling to create activities which are meaningful has the average least amount of time spent. There is no eye contact and no sign of recognition or awareness.As a result the member of staff gets very little satisfaction. Child J and Child JB give the most visual and auditory responses even though they are immobile.They have the ability to make meaningful contact thus giving staff the satisfaction of gaining a result thus boosting motivation.Diagram 1 in fact places children in ability to respond order. These points were clarified in discussion with the staff,who were unaware that this happened.

It is interesting to note that the first hour and the third hour has more time on task than off task.Considering that hour one begins the school day and hour three begins the afternoon session,it could be argued that the staff begin the day with determination but motivation wanes when responses fail to materialise.The same might apply to the afternoon session. The results reflected a reduction of time on as the hour sessions progressed.This applies to all with the exception of the final hour where the most input for time on task came towards the end of the session.

An additional concern is the attendance factor.During this observation on no occasion was there a full class group of 14. This being the case,these results,which illustrate low time on,would possibly have been worse with a full group.The converse is also a possibility.If time on is a reflection of staff motivation perhaps with a full class the need to work with more children in the same periods of time may benefit the situation.It is clear that more research is necessary to clarify the position.

While these observations appear to be very negative there were many positive activities.All staff worked very hard and at a tremendous pace,constantly giving a great deal of thought to each activity and childrens needs.They related well to the children,always talking to them,and to each other and were a very good team.Each appeared to know instinctively what to do.There was some excellent group activity observed which may well be a pointer to modifications which may increase the time on task for the children.

As a result of the project, discussions and brainstorming produced areas that needed to be considered. As a group it was decided that the staff needed to find different ways to organise the room,themselves,and make better use of other professionals and parents. Many of the ideas have now been implemented

This short project has raised issues that need to be addressed.Children with P.M.L.D.have been integrated into the Education system now for some twenty years and while research and literature tell of what to do and how to do it no one has come forward with a theory of how long they should be doing it.The issue of time on task needs addressing as a matter of urgency.

While the initial project was that children with P.M.L.D. spend disproportionate periods of time off task as opposed to on task,it became a secondary issue when it was observed that what was required was the reorganisation of rooms,staff and resources in order to improve classroom management skills and techniques.By improving the tasks of staff and the responses of children, greater satisfaction and motivation would result in more time on task .This would ensure better educational provision, providing that the tasks were the right ones.

ALLAN HOWKINS JUNE 1992
DUDLEY,WEST MIDLANDS.

Letter written by Barbara Ackerley and Jeanette Lomas of Birmingham University to Louise Clunies-Ross of the Royal National Institute for the Blind, in January 1992.
Letter written by Barbara Ackerley and Jeanette Lomas of Birmingham University to Louise Clunies-Ross of the Royal National Institute for the Blind, in January 1992.

Mrs. Louise Clunies-Ross,
Assistant Director,
Policy Development and Information Services,
Royal National Institute for the Blind,
224 Great Portland Street,
London W1N 6AA

Dear Louise,

Re - The Parent's Charter

Barbara and I met on Tuesday evening and we would like to make the following points about the Parent"s Charter and relevant documents, in connection with children and young people who are multihandicapped and visually impaired. Many of the points we make are applicable to all children who have severe learning difficulties and are not only relevant to the MHVI.

i) Parents as Partners has, for a long time, been the message of those working in Special Education, and therefore we welcome the philosophy of the charter that encourages parental involvement in every sphere of Education. Parents have the right to know about their child's school, progress and general development but we question the need for **everyone** to have access to such information. Only those parents who have a child who is MHVI are in a position to state the feelings they experience at the various significant stages of their child's school life, e.g. starting school, changing classes to a new teacher, transferring schools, making that enormous transition from school to adult services, however, we think that by publishing comparative results there will be a compounding effect upon the guilt already experienced by the majority of parents.

ii) In the Charter Special Educational Needs is dealt with on a separate page, and appears as an after-thought. Warnock(1978) stated that an estimated 20% of children would have special educational needs during their education. Printing such statistics at the beginning of the section would have been helpful because, in our experience, parents feel extremely isolated when they have a child who has a disability and/or learning difficulties and they think they are the only parents of a child with special educational needs.

iii) The location of the section about SENs is unfortunate. Parents will read on earlier pages, about their rights of choice of school etc. when in reality the choice for children with MHVI is extremely limited. Due to the low incidence of such disabilities the choice of suitable schools, with appropriate teaching methods, staffing levels, access etc. will not be available. The lack of finance, experienced by many LEAs, has seen the growth of unwritten policies which prevent many children being educated outside their authority. There is a 'needs' verses 'provision' issue here, because the charter clearly states that "the local council (will) pay for the place if the school charges fees."

iv) We feel uncomfortable about the intention to publish children's attendance records. Many MHVI children spend long periods in hospital or, due to their general level of health, do not attend school when there is inclement weather.

v) The aim to employ "independent inspectors" to identify the strengths and weaknesses of schools will require inspectors to have knowledge of the differentiated curriculum for children who have SLDs. Therefore we would like to see the words "with appropriate skills and experience" added.

vi) "Performance Tables" as described in the charter are totally unsuitable for schools where there are children who are MHVI. "Records of Achievement" are far more positive. Our children have an entitlement to the NC but their performance levels will not be the same as those of mainstream children. The child with multiple disabilities will need longer to achieve, the gap in performance levels highlighted by the tables will increase as the child gets older, and may cause a delay in the acceptance of the child's disabilities by the parents.

vii) The aim to include school leavers' destinations may also create difficulties for parents. In reality there is not the variety of destinations available, in fact many young people leave school at the compulsory age and have to stay at home with their parents.

viii) Many F.E. colleges are developing courses for young people with special educational needs. We question whether this area of growth will continue if examination results etc. are to be published. It would be encouraging to see the development of information sheets which record broad achievements throughout the colleges without the emphasis on academic excellence.

ix) The information given about Special educational needs does not appear to give the impression that there is a collaborative approach to assessing SENs. The tone is one of conflict not collaboration. Parents of children who are MHVI will be part of a multidisciplinary team, with valuable contributions to be made, however they are not always in the best position to identify all the needs of their child due to the complexity of multidisabilities and the time it takes for children who are MHVI to learn. At the time of the assessment of SENs many parents are still coming to terms with their own feelings and will require support not conflict.

Children and young people who are MHVI have the same entitlements as children in mainstream schools. Parents of MHVI children have a right to relevant, realistic information which demonstrates that their child has a place in the education system. Photographs of SENs young people learning would have been appropriate.

We hope our comments will be of help when writing to the DES.

Yours sincerely,

Barbara Ackerley and Jeanette Lomas

INCLUSIVE EDUCATION

Having recently attended two conferences on inclusive education, I was somewhat concerned that the only option for the "evangelists" is the closure of all special schools. Any half-measures by professionals and parents who have reservations about some negative aspects of restricting the choices available are tantamount to heresy.

At the "Great Integration Debate" which took place in the Granada Studios House of Commons stage set, those in favour of closing all special schools gave examples of PMLD pupils who had no head control even after years of physiotherapy. After two weeks in a mainstream school, this was apparently achieved by one child.

We also heard from two young women whose learning potential had only been recognised since leaving a segregated system. One woman is currently studying for a masters degree in computer studies.

We heard of schools for pupils with severe learning disabilities which provided poor role models, where teachers were not geared for the diverse needs of these special pupils and where they were a dangerous environment for pupils with PMLD.

We also heard counter arguments from speakers and members of the "House" who did not recognise the schools described and who considered that the arguments for closure were oversimplified. Special schools were established initially because mainstream schools could not provide the education which fulfilled the needs of those with mild and moderate learning disabilities, let alone those with profound and multiple learning difficulties.

Argument and counter argument were put forward, yet at the end of the day the motion for closure of special schools was not put to the vote. I suspect that if it had been, it would have been defeated by quite a significant majority. This is not because those present were against integration or inclusion. From all the comments made there seemed to be a genuine desire to extend the choices available to those children and young people with severe and profound and multiple learning difficulties. Mainstream schools should be an option, not the only option and that option should be more widely available than it is.

PMLD Link is a forum for exchanging information and providing sources of good practice in provision for people with profound and multiple learning difficulties. It would welcome examples of successes and failures of schemes for integrating people with profound and multiple learning difficulties so that we can all have a more objective understanding of the main issues.

Please write to PMLD Link and offer your experiences and views.

Helen Mount
Co-ordinator
Mencap PIMD Section, Manchester

BOOK REVIEW

"I Can Do It!"

A learning package of software and user guide. Published by Barnardo's, in association with Edge Hill College of Higher Education.

This learning package has been produced to fill a perceived gap in the computer program market, and offers software appropriate to the needs of children and young people with profound and multiple learning difficulties. The software has resulted from a joint interactive learning project carried out between Barnardo's and Edge Hill College of Higher Education. Using the computer as the interactive medium, programs were developed which laid particular emphasis on the sensory elements of sight, sound, and touch.

Just how do you review and evaluate software such as this, designed for children with profound and multiple learning difficulties? What to us, with our hierarchical skills may seem perfectly acceptable, may be unstimulating and inaccessible for the child with profound multiple learning difficulties.

With the help of some of the children at Merstone and Reynalds Cross Schools, Solihull, we trialled these materials. Here are some of their "comments" (their responses were noted in detail by their teachers), on each program.

"Swans" : Nicky became very vocal when watching this program. David was so motivated that he continuously reached out to press the single switch. Tracey smiled throughout.

"Cygnets" : Nicky was less interested in this program, whereas David made a lot of body movements. He managed to sustain his gaze towards the screen, and reach out at the same time. Sarah watched the screen, but did not make any attempt to touch the screen.

"Doggy in the Window" David and Luke both smiled when they heard the music, but the visual effects did not hold their attention for more than a few seconds.

"In the House" : Sarah smiled all the time as she watched this program. She touched the screen, unprompted, many times. David's eyes followed the movements of the tap and cup.

"Twelve Days of Christmas" : Nicky made 'mmm' sounds throughout, and laughed loudly at the hens. Sarah watched (but did not smile) and let her head drop at "5 gold rings".

"Happy Birthday" Gary watched this closely and touched the screen first time through, but was less interested second time and became restless. Nicky screwed up his face, as if to see the small graphics, and did not demonstrate any visual response when the candles were blown out.

"Dylan" Nicky's teacher thought this would be a useful program; Nicky's lack of movement suggested he didn't! This opinion was shared by Gary and Sarah who also did not respond in anyway to this program.

All of the above "comments" were made about the single switch level for each of these programs. At the two switch level, high levels of interaction were observed when the pupils engaged in the program "In the House". At the third level (multi-switch choice) the teachers felt the programs were more suited to children with SLD than those with PMLD, and they thought the programs would be useful in a variety of ways. The children who did participate in the "Susie" and Scales" programs were all attentive, but less interactive vocally or physically. Overall, the teachers liked the teaching sequence of watch, listen and touch. The documentation they found very user friendly.

Barry Carpenter
Inspector of Schools
(Special Educational Needs)
Solihull LEA

Diary Dates RNIB activities

8 July 1992 - Leeds, **Vision Motivation, and Movement** - A study/activity day for staff. The morning will look at work with people with severe physical disabilities, the afternoon at developing independent movement in people who are ambulant.
£60.00

Details from RNIB Information Service on Multiple Disability - Gill Levy/Julia Wensley, Telephone 071-388 1266 ext 2449/2275.

2 September 1992, Strathclyde University, **Introduction to Multiple Disability** (Day 1)
£50.00 - non-residential

3 September 1992, Strathclyde University, **Assessment of Visual Function and Developing Communication Skills with Multiply Disabled People** (Day 2)
£60.00 - non-residential

4 September 1992, Strathclyde University, **Movement and Mobility for Multiply Disabled People** (Day 3)
£60.00 - non-residential

Details from RNIB Training Service on Multiple Disability - contact Mark Gray/Janice Evans. Telephone 021 643 9912.

24 September 1992, London, **Assessment and Planning Intervention** -study day for psychologists working with adults with visual and learning disabilities.
£60.00

Details from RNIB Information Service on Multiple Disability - Gill Levy/Julia Wensley Telephone 071 388 1266 ext 2449/2275.

21 October 1992, Whiteabbey near Belfast, **Introduction to Multiple Disability**
(Day 1)
£50

22 October 1992, Whiteabbey near Belfast, **Assessment and Communication Techniques with Multiply Disabled People.**
(Day 2)
£70

Note: £160 both days with 1 night's accommodation

Details from RNIB Training Service on Multiple Disability - contact Mark Gray/Janice Evans. Telephone 021 643 9912.

27 November 1992, London, **Assessment and Communication Techniques with Multiply Disabled People.**
£60

Details from RNIB Training Service on Multiple Disability - contact Mark Gray/Janice Evans. Telephone 021 643 9912.

14 and 15 December 1992, Birmingham, **Aromatherapy and Massage with Multiply Disabled People.**
£160 - non-residential
£200 with 1 night's accommodation

Details from RNIB Training Service on Multiple Disability - contact Mark Gray/Janice Evans. Telephone 021 643 9912.

7 January 1993, Durham, **Introduction to Multiple Disability**
(Day 1)
£60

8 January 1993, Durham, **Challenging Behaviours in People with Sensory Disabilities** (Day 2)
£60

Note: £180 both days with 1 night's accommodation

Details from RNIB Training Service on Multiple Disability - contact Mark Gray/Janice Evans. Telephone 021 643 9912.

2 March 1993, London, **Vision Motivation, and Movement** - A study/activity day for staff. The morning will look at work with people with severe physical disabilities, the afternoon at developing independent movement in people who are ambulant.
£60.00

Details from RNIB Information Service on Multiple Disability - Gill Levy/Julia Wensley, Telephone 071-388 1266 ext 2449/2275.

POST-SCHOOL PROVISION

At a recent workshop on transition from school to adult provision, the dire lack of services for people needing the degree of support that our students require was reported by virtually everyone. It was agreed that one reason was the complete ignorance of their existence by those people who made decisions and allocate funding and, in particular, members of the government and opposition.

A letter has been sent to MENCAP to enlist its support in raising awareness of the needs of our students, and one suggestion is for every subscriber to copy PMLD-Link and send it to their own MP, perhaps with a covering letter.

Can you do this?

Academic Year 1992/93

PMLD Link

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