

PMILD 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***

BUSINESS MATTERS

This issue focuses on working with parents, but we are conscious that virtually all our subscribers are professionals working in the statutory or voluntary services although this does not, of course, exclude you from being parents as well. If you have any ideas about how we can reach more parents and make PMLD-Link useful for carers and families, we would be very glad to hear from you.

PMLD-LINK CONFERENCE: Interest in the conference has been very encouraging so far. As places are limited, if you intend to come to the conference, do send in your booking form in good time to avoid disappointment. Please let other people know about the conference if you think they may be interested - it is not restricted to readers of PMLD-Link!

REGIONAL CONTACTS: The editorial group have been setting up a network of regional contacts, to help people to link up and share ideas, and also to keep us in touch with what is happening across the country, and how people would like PMLD-Link to develop. A list of regional contacts is being prepared, and will be available at the Conference on 15th October. It will also be sent out to all subscribers in a later issue. We hope you will get in touch with your local contact or, if there is no-one in your area, either nominate someone or fill the gap yourself.

NEXT ISSUE: The next issue is focusing on sensory work and sensory environments. This is a topic which has a high priority in working with people with PMLD, and Barry's editorial offers a refreshing perspective, challenging us to think carefully about precisely what we are doing, and why and how we are doing it. I hope that it will inspire many of you to write about your ideas and experiences, or let us know of equipment and materials that you have found particularly useful and relevant to your pupils, students and clients.

CHANGE OF ADDRESS: Most of you will know from the slips sent with the spring issue, that the date for the change of address is 1st July. The move has concentrated my mind marvellously on getting the summer issue out to you in good time before the summer break! All future contributions, and I do hope there will be many of them, should be sent to me at the new address at the bottom of this page.

SUBSCRIPTIONS: September is the time when all subscriptions are due for renewal for the 1994/95 year. We have kept the subscription at the same rate for UK subscribers, but I am afraid the rate for overseas subscribers has increased to cover the extra cost of postage which is considerable, even to EC countries.

Some subscribers have already paid their next year's subscription, but if you have not yet done this, please send the form and your subscription to the new address before the next issue is due in November.

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FINDING A HOME FOR THE SENSORY CURRICULUM

Alongside major statutory educational initiatives during the last six years, there has been substantial development in the use of sensory approaches in the education of people with profound and multiple learning difficulties. A major protagonist of these developments has been Flo Longhorn who, through her writings and in-service work, has done much to stimulate what she has termed the 'Sensory Curriculum'.

Curriculum, as we should constantly remind ourselves, is a process not a product, and it seems timely that the Sensory Curriculum should come under review. The theme for the Autumn issue of *P.M.L.D. Link* will be 'Sensory Environments'. Many schools have invested considerable amounts of time and money (often collected through hours of fund-raising) in Dark Rooms, Sensory Rooms, Light Rooms, White Rooms and Soft Play Rooms. After the initial excitement of installing and experimenting with these stimulating environments, it seems timely to reflect critically upon the use of these rooms and the contribution they are making to the curriculum for learners with p.m.l.d..

Has the Sensory Curriculum found a home? Does it have a secure place in the Curriculum? Is it resources driven? Or facilities driven? (It's Wednesday afternoon, and your class is timetabled for the Sensory Room, so use it you must.)

Indeed, is the Sensory Curriculum a discrete element? Or should we be looking at sensory approaches to teaching and learning which permeate the curriculum offered to learners with p.m.l.d.? In conducting some school-based action research recently with two teachers in an S.L.D. school, these were some of the questions I asked myself. Nicky Moss in her analysis of the Sensory Curriculum, has identified that it is used for two distinct purposes. Either for individual sensory stimulation programmes or as a vehicle for access and enhancement for other areas of the Curriculum. She argues strongly for a permeated approach. Indeed, I would conjecture that sensory approaches should act as a key learning support strategy for learners with p.m.l.d. in all curriculum areas.

Julia Sims in her study developed a model of planning which purported that in the National or Developmental Curriculum, sensory approaches have a fundamental place in ensuring that the individual needs of the learner with p.m.l.d. are met. Flo Longhorn (1993) illustrates in one of her recent publications how the sensory dimension is a key prerequisite to learning for the child with p.m.l.d..

This is so across the age range, as the MENCAP Leisure Pack vividly illustrates. The recently published MENCAP/F.E.U. *Learning for Life* pack demonstrates how we can confer 'Adult Status for All', and that sensory approaches, in the form of adult leisure activities such as aromatherapy, massage or beauty therapy, can contribute to this goal.

Sensory approaches can facilitate differentiation in the curriculum for learners with p.m.l.d.. They present us with six (let us not forget kinaesthetic input) learning modalities through which we can teach, and six response modalities through which the learner with p.m.l.d. can communicate their thoughts, feelings, needs and moods.

We would be pleased to hear of sensory developments in your school or centre, and your thoughts on the contribution that sensory approaches can make to the education of learners with p.m.l.d..

One final request: the Editorial Team are planning an International Issue of *P.M.L.D. Link* in the Spring of 1995. Obviously we need to start seeking contributions for that issue now. If you have friends or colleagues working with people with profound and multiple disabilities in another country then please do encourage them to write a short piece for *P.M.L.D. Link*. Indeed, you may be planning a trip abroad where you may get an opportunity to observe educational provision for those with p.m.l.d.. Do share what you see with us.

Wherever you are this summer vacation, I hope that it is a relaxing and refreshing time, and that you return next term full of enthusiasm for the exciting challenge of educating learners with profound and multiple disabilities.

June 1994

Barry Carpenter
Westminster College, Oxford

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Support for Parents of Pre-school and Nursery aged Children

Until quite recently I was Area Co-ordinator of a Pre-school Support Service for children with special needs, home visiting families on a regular weekly basis. The service model, based on the principle of partnership with parents, was similar to the Portage model. Key elements underpinning the service were support to families, partnership with parents and other professionals and an inter-disciplinary approach.

Effective communication is vital in this work, especially in the early years when parents are receiving information from a number of professionals. One family I visited had encountered 12 professionals during a week.

Local Authorities and many professionals all increasingly taking the initiative in developing ways of communicating with parents. Inspired by the Greater London Association for Disabled People (GLAD) 'A Joint Endeavour' (1988) I carried out an investigation between parents and professionals at the time of the Formal Assessment Procedure (Section 5, 1981 Act) for pre-school children with special educational needs. (Since the new Code of Practice, this statutory Assessment is now Section 167, 1993 Act).

My research aimed to investigate the hypothesis that relationships being established will enhance the partnership role between parents and professionals by helping to:

- a) Clarify parent - professional expectations.
- b) Promote parent - professional rights and responsibilities.
- c) Jointly highlight areas for development

(Copies of Masters Dissertation available from C. Simons, 17 Lambourne Crescent, Chigwell, Essex. £10 + p.p. (Simons. 1993).

The professionals' contribution to the relationship was certainly recognised as assisting coping through the provision of information, guidance and emotional support. From listening to the parents and professionals involved in the Formal Assessment Procedure (F.A.P.), through observing them and by interviewing them, I was able to self reflect and improve my own working practice.

In my present position, working in the Nursery of Whitefield School for children with profound and multiple learning difficulties, I continue to work very closely with families who are embarking on the F.A.P. with their children.

1. Before entry to the Nursery the parents and the child are invited to visit, have a look around and ask questions about the school. Vital information is gathered at this time from the parents about their child.

2. We have an 'open door' policy from day one so that parents and staff can get to know one another and build a trusting relationship.
3. We listen to the parents. We value their opinions and continue their good work with their child.
4. Both parties use a home/school book daily so that we can share detailed information on the child.
5. We are able to offer formal and informal meetings about the Formal Assessment Procedure. The Whitefield Family Support Service arranges parent workshops on the above on a regular basis.
6. We offer home visits and joint home visits with other professionals whilst Advice for the Assessment is being gathered.
7. Time is available for the parents, not only for the preparation of F.A.P. but for sharing daily 'highs and lows'.
8. We also offer a range of written information on F.A.P. and a check list through the process.

Parents are satisfied with the help and advice we are able to offer them at this stressful time. What we offer are not particularly new initiatives or strategies, but they are proving successful.

We offer our time and value the parents and children as individuals.

Parents value being listened to, quotes from parents include:

"listens to me, never rushes me if I don't understand"

"listens to what I have to say about my child"

"I know she values my child as an individual in the same way as we do"

"Gave me confidence, acknowledged the fact that I know my child best"

"Gave us information and helped us at each step of the way".

One parents' comment on F.A.P. is poignant " I've dreaded the whole process. No matter how well you are prepared with talks and paperwork you need someone to help and support you through the whole worrying performance. We were lucky".

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THE EFFECTS OF A MULTI-SENSORY IMPAIRMENT ON THE PROCESS OF BONDING/ATTACHMENT BETWEEN CAREGIVER AND CHILD

Families of children who have handicapping conditions are often faced with a unique set of problems as they attempt to adapt to the presence of a handicapped child within the family unit.

This article is intended to bring together the parental stresses caused by the diagnosis of a multi-sensory impairment and how interaction between mother and child may be affected by the presence of such an impairment.

Limited research with multi-sensory impaired children indicate that impairments of hearing and vision renders this population very vulnerable in the development of adequate attachment behaviour (Friaberg, 1975, Burlingham, 1975).

Individual differences in the quality of infant-mother attachment have been formed in recent years to forecast individual differences in subsequent child functioning. Chazan and Laing (1972) report 'Mother and child interaction lays the foundations of the feelings of competence which the child develops and which influences later adjustment' (P.101).

In the care of the severely handicapped multi-sensory impaired child disruption to the infant/mother bond can occur very early in the child's life. Mother-child interaction may be stopped at the very beginning by separation of the child from his mother. The baby may be taken to the special care unit of the hospital because of prematurity or serious illness. This increases the chances that mother and baby do not have much opportunity to interact in the early days following birth.

Premature birth can be a traumatic experience for a mother, low birth weight is worrying. Mothers anxiety may be due as much to these and related factors as to her enforced separation from her baby.

To be discharged from hospital and return home without her baby is a situation fraught with difficulty for any mother. When she learns that her baby is handicapped at birth she will, of course, be naturally affected by the news. The initial emotional reaction of mothers has been found to be anxiety, shock or dismay in facing an unexpected crisis. She may well be disappointed with her baby or herself, which in turn, can lead to enormous difficulties in establishing contact between herself and her baby with the result that a normal bonding does not develop.

Klaus & Kennell (1976) assert that '..... the intimate mother-child contact in the sensitive period' gives rise to a host of innate behaviours, in their words, 'a cascade of reciprocal interactions begins between mother and child which locks them together and mediates the further development of attachment.'

When a physical abnormality is identified at birth there is some evidence that the parents initial attention to the baby's bodily appearance and functioning will be intensified. In the case of many multi-sensory impaired children the disability or further disabilities may only become apparent as the child's development does not take its expected course. In some cases the disability may only occur after birth as a result of a viral infection. As the child grows the discrepancy between normal development and the handicapped child's development increases. Parents are now very vulnerable. They are confronted with a situation outside their experience. Because of their limited knowledge of the consequences of their child's condition they are often uncertain in dealing with their child. In many situations they cannot - like the parents of a sighted and hearing child trust their experience gained through rearing siblings. Often there is no one in their environment they can turn to for child rearing advice.

More time will need to be devoted to the management of the multi-sensory impaired child than would be anticipated for a non-handicapped child. It may be difficult to keep the balance of attention to the rest of the family. However, the consequence of affectionate acceptance of the child as he is may be crucial in helping him to capitalize on subsequent education and social opportunities.

There may be many reasons for the parents preoccupation with their child's physical impairment at the expense of fulfilling the overall needs of the child. The additional attention and care needed because of the impairment will require time and energy which could otherwise be devoted to the child's social or intellectual development. The multi-sensory impaired child is often perceived as and often is a very sick child. The child's education is often disrupted by long periods of treatment. During this time he/she is often removed from parents and may be subjected to long periods of painful treatment.

The issue of separation is an especially important one for such a child since this has potentially serious consequences for the social development

of the child. Fraiberg (1977) pointed out that separation may have serious implications for the blind child as (1) "We have a child whose own adaptive capacity to sustain loss is diminished by blindness and (2) We have a mother who must deal with a developmental crisis in her blind child's experience without anything in her own experience which can help her to understand the extraordinary significance of loss to a blind child" (P.359).

It is crucial to ensure that separation is not interpreted as rejection. It would seem that the greatest hope for success in these situations lies in effective counselling for parents, a point made in the Vernon Report (1972). 'A basic aim in providing advisory services for parents whose children are visually handicapped must be to help diminish the anxiety and apprehension of parents and encourage them to provide an environment that encourages the independence and active curiosity of young visually handicapped children.

As we have seen the mother of a sensorily impaired child may well be subject to considerable physical and emotional strain, the early mother-child relationship may be at risk of being disturbed if handling of the child is minimised due to medical reasons or a long stay in hospital. A cycle can be set up in which the child lacks security and so resists handling only to be hypersensitive to handling. Sensory deprivation is common amongst sensorily impaired children firstly because of reduced handling and because of the difficulty some parents have in intervening physically and relating emotionally with their child. Selma Fraiberg, the child psychoanalyst and social worker who conducted extensive studies on how to help mothers with blind babies suggests that parents may be inhibited in touching, cuddling and talking to their children because their visual impairment interferes with the normal affective interaction between parents and child. Fraiberg (1977) remarks - 'The absence of eye contact gives the negative sign of 'no interest'. The gesture 'hold me', 'pick me up' does not appear till the end of the first year. The babies sign vocabulary of selective interest and valuation of his human partners which constitutes the earliest language of love is distorted for the mother of a blind baby?

For the blind child the establishment of human ties is not the easy automatic event it is for the sighted baby. Many of the age-old signs interest, pleasure and affection are not easily available to the blind baby nor easily recognised by parents. In the absence of response there is less expectation of response and gradually fewer attempts to elicit responses.

Parents may feel increasingly out of touch with their baby and a spiral of estrangement and withdrawal may begin. The problem for many parents is that grief, guilt, fear or simply not knowing how to handle their baby can lead to a social distancing and make it impossible for parent or child to enjoy mutual responsiveness. Until closeness is established the child will be unable to establish vital links with his environment.

McInnes & Treffrey (1982) write 'Regardless of what type your multiply sensorily deprived child is, the first step is to make contact with him and to establish an emotional bond'.

The lack of synchrony between mother and child in early infancy can have long lasting effects on the child developing communication skills. A lack of visual acuity has a crucial impact on the development of early communication. The two most significant factors in the development of communication appear to be the establishment of reciprocal gaze patterns between child and caregiver and the infants subsequent smiling behaviour. Clearly the interactional process is affected if these fail to appear in the child's repertoire. The progress of early communication development is centered within the interactions and relationships between child and caregiver. Through a stable and nurturing relationship with their caregiver children develop a sense of security in their world. This contributes to children's confidence in exploring the environment and out of this confidence a firm base is established for future attempts at communication. The importance of social interaction and social contact for early communication is promoted by the fact that children learn their behaviour has communication significance and effect upon the responses of others (Bakeman & Adamson, 1984).

Sight and hearing are also important for early social and psychological development. Physical closeness to either people is a prerequisite for normal development. The non-handicapped child discovers how to maintain closeness through sight and hearing. He can explore with mother close by. The deaf-blind child cannot locate mother over a distance if she moves. Absence of emotional attachment is common in congenitally deaf-blind children. Instead, they often show a mechanical interest for people and are without the initiative to act except with behaviour that is self-stimulating and repetitive.

Severe sensorily impairments also impose restrictions on social and environmental interaction. The constraints on the range and variety of experience and control of the environment have profound effects on the development of the child.

'Babies with limited response repertoires have an inhibiting effect on their parents' (Bricker and Lewis, 1982). The more handicapped children have fewer resources available through which to initiate interaction. Unresponsive infants elicit fewer responses from adults.

Social interaction is disrupted by lack of eye contact and other signal type behaviours. Not only is the child's ability to match his mothers face impeded by his disability but his mother's experiences difficulty reading her baby's face because of his undifferentiated facial expression - a difficulty which understandably arouses considerable anxiety in mothers particularly when the child is distressed and the mother is unable to determine the reason. Blind baby's behaviours affects mothers more strongly than mothers behaviours affects the baby's.

In the education of the sensorily impaired child the development of attachment has become a more and more vital issue. In the process of bonding vision plays a dominant role as can clearly be observed in attachment characteristics such as smiling, stretching out arms when familiar people approach and eye contact.

It is for this reason that we, as educators, working with multi-sensory impaired children place such importance in our earliest work in promoting attachment behaviours between the child and his primary carer.

The emphasis in the Early Years Centre for Multi-Sensory Impaired Children, where the writer is currently employed, is to focus upon the parent-child interaction process as the touchstone for our intervention programme. It is through this approach, directed to the unique needs of each child and their families that attachment behaviours are developed.

Bricker & Carlson (1982) have implicated a crucial role for early reciprocal interaction in the infant's acquisition of communication and language. The importance of early parent-child relationships is also reflected in several language intervention models that stress the social basis of language

development (McLean-Snyder-McLean, 1978).

Emerging evidence suggest that disturbances in mother-child interactions in early infancy may lead to developmental difficulties later in infancy. Parmelee & Marcy (1976) have reported a strong relationship between problematic interactions between mother - preterm infants at one month and low scores on sensori-motor assessments at nine months.

Emphasis is placed in the Early Years Centre upon the parent-child interaction process along with several critical dimensions of the conversational nature of that process. These include structuring activities in order to increase turn-taking and ongoing interaction. Following the child's lead provides a strategy for imitating or maintaining turn-taking in the interaction. Imitation of the child provides a means of beginning or maintaining a turn-taking sequence. Waiting for the child's turn constitutes a sequence to initiate or maintain turn-taking. The focus of intervention is upon characteristics of the child's interactions with persons and events in his environment which are essential for optimum development. The day to day caregiver-child interaction process is conceptualised as providing the context for the child's acquisition of skills pertinent to his cognitive, communicative, perceptual and social - emotional development.

As well as providing the basis for the child's educational programme this interactive model is shared with the families to enable them to gain pleasure and confidence in the management of their child as well as ensuring consistency between home and school.

Mary Jones - Teacher employed with the Pre-school Team, Solihull, currently on secondment to Early Years Centre for Multisensory Impaired Children in Birmingham.

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A SPECIAL LINK

A regular visit from a person who shows an interest can make a considerable difference to the life of a person with a learning disability.

For individuals with no visiting friends or relatives, an advocate provides the means for their partner to enjoy everyday activities. By representing their partner's interests as their own, an advocate encourages their acceptance by society as an individual with the same rights and needs as everybody else. Without a representative and friend, many people with a learning disability are effectively isolated and excluded from community life - an advocate can be the link.

Citizen Advocacy Alliance works in four long-stay hospitals in the south London area and in their surrounding communities of Sutton, Merton, Epsom, Croydon and Richmond. The role of their Development Officers is to identify clients who would benefit from an advocate, to recruit and train volunteers and to match the needs and interests of each party to encourage a long-term partnership which will ultimately improve the quality of life of the client.

Most advocates have not had previous contact with people with learning disabilities and the prospect of partnering someone with severe disabilities or challenging behaviour can be very daunting. However, care workers, therapists and other professionals involved in the field of learning disability are potential advocates who could utilise their particular skills or experience for the benefit of one particular person, especially where there are difficulties with communication.

Being an advocate involves spending a couple of hours a week getting to know someone on a one to one basis to try to understand and interpret their needs. Offering long-term practical and emotional support to their partner can make a considerable difference to their quality of life.

If anyone is interested in finding out more about Citizen Advocacy or about the advocate's role, please contact Teresa Howes on 081-643-7111.

THE ROLE OF A DEVELOPMENT OFFICER

AT THE WHITE TOP CENTRE

The White Top Centre, Westfield Avenue, Dundee is a purpose built centre, which represents a tremendous advance in facilities for people with profound and multiple disabilities in Tayside. The Centre offers an example of close collaboration between agencies with input from Tayside Regional Council Social Work Department, the University of Dundee, Dundee Health Care Trust and two charitable foundations, the White Top Foundation and the Gannochy Trust. While provision will be made for 15 people at the outset, it is hoped that the White Top Centre will benefit a larger number of people with profound and multiple disabilities through assessment and advisory services.

The role of Development Officer involves liaison between the White Top Centre, families, carers, community agencies and other facilities utilised by our service users. The creation of such a role confirms the value and importance of all the significant people and services presently involved in the lives of our service users, and emphasises our commitment to their active participation in the future service development at the White Top Centre.

In order to establish the role of the Development Officer, the above values need to be translated at every step into a practical realisation. For the purpose of this article, we shall focus on collaboration with parents, outlining the working model, whilst in a future issue of P.M.L.D link we can concentrate on the other distinct part of my role, which is the development of community links.

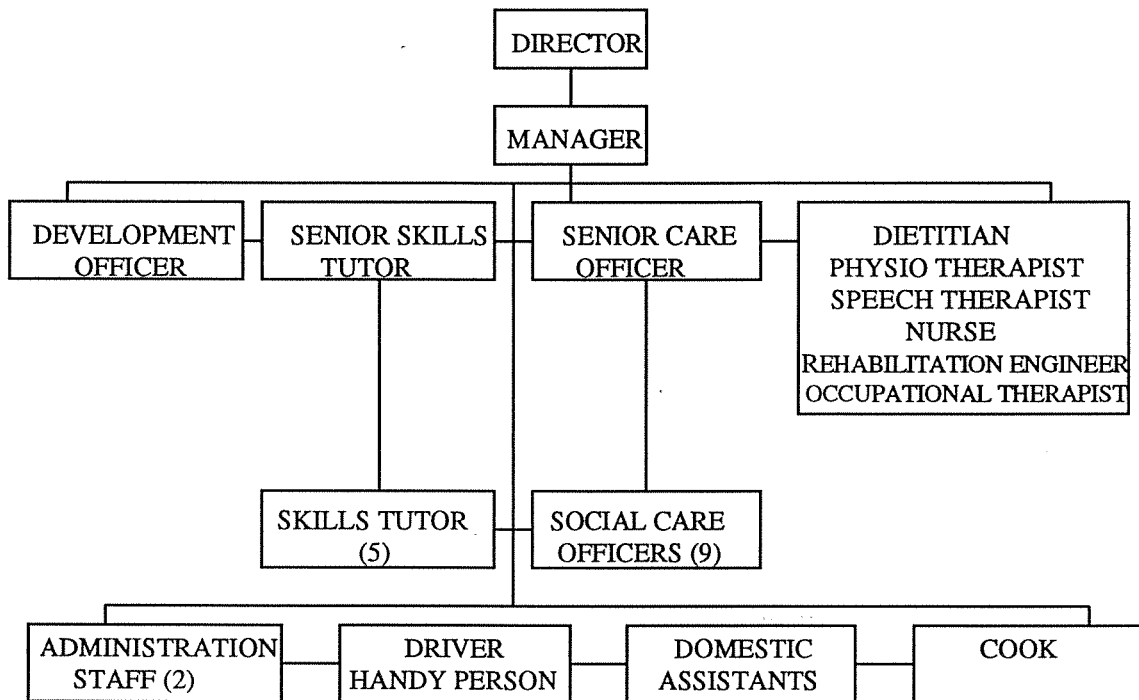
Therefore, the first and most obvious question we need to address is: WHAT CAN A DEVELOPMENT OFFICER OFFER PARENTS? The present Community Care legislation commits service providers to put people, who are the focus of community care provision, in charge of their lives to the maximum degree possible. Accordingly, at the White Top Centre we intend developing a holistic approach to our service user's curriculum. This approach means that all the programmes of work with each individual will be highly integrated across the different types of service input and settings including the person's home.

An integral part of our curriculum planning will therefore involve parents and carers. In order to address and acknowledge one of the central problems facing parents, namely activating and co-ordinating services for their son or daughter, or more rarely themselves, we feel it is a pro-active move to have a Development Officer as the key person to facilitate their ability to access services, and have direct input to them.

HOW CAN A DEVELOPMENT OFFICER CO-ORDINATE PARENTS INPUT

To maintain a high quality professional - parent relationship, the Development Officer needs to function in a management team which recognises the uniqueness of the role.

The operational structure at the White Top Centre is geared to enable the Development Officer to have the freedom to develop the breadth of the curriculum with parents, without the day to day tasks normally associated with such a management position. The diagram below outlines the management structure.



The Development Officer is therefore part of the Senior Management Team, but without line management responsibilities. This structure reinforces parent support and collaboration within the White Top Centre. Through the Development Officer, an effective input from other agencies is also insured.

HOW DOES THIS APPROACH ATTEMPT TO ACHIEVE POSITIVE OUTCOMES WITH PARENTS?

The curriculum and operational structure at the White Top Centre afford the Development Officer an innovative role with parents because they offer equality and status to parents, thereby alleviating the stress by sharing information, and most importantly accessing quality services quickly.

The above points are central to the further development of our relationships with parents because it encourages their participation, expansion of their views and choices, in a way that does not discourage or inhibit development of knowledge relating to their daughters or sons.

To illustrate Parent / Development Officer collaboration in practice, a summary of participation in the transition of a service user to the White Top Centre is detailed on the following page.

PARENT PARTICIPATION IN THE TRANSITION PROCESS

TRANSITION PERIOD - Fifteen weeks

INPUT

Thirty hours of contact and collaboration time between parents and the Development Officer.

PROCESS AND PREPARATION FOR ANY PARENT CONTACT

- I) Negotiate a choice of venue.
- II) Negotiate a convenient time for parents - Home Visits - 6 pm
White Top Centre Visits - 10 am
- III) Discuss parent's transport needs to participate in transition process - White Top Centre transport not required as parents can provide their own transport.

DISCUSS STAGES WITH PARENTS PRIOR TO TRANSITION

- I) Initial contact by the Development Officer to discuss parent's view of transition process.
- II) A transition assessment from the parent's view point is formulated. The Development Officer agrees to write up assessment.
- III) The written assessment is cross-checked by parents.
- IV) Discuss and cross-check transition information from service user's present establishment.
- V) Information co-ordinated into an agreed transition package.
- VI) Parent input to White Top Centre during initial stages of transition is negotiated and agreed.

PARENT INPUT TO THE WHITE TOP CENTRE DURING TRANSITION

- I) Initial evening visit to familiarise parents, staff and service user with the new environment.
- II) Participation in service user's first three days as parents and professionals agreed.
- III) Negotiation of parents withdrawal from transition process is left flexible. Parents choose to withdraw after three days.

- IV) Informal review held after one week.
- V) Parents indicated that the transition process was a pro-active experience from their viewpoint.
- VI) Review indicated a pro-active transition for the service user.

ACCESS ISSUES

- I) All requests for parent contact arranged within one working day during transition.
- II) Parent's request for access to other professionals also arranged within one working day.

CHOICE

- I) Parent and professional information negotiated into a collaborative package.
- II) All significant stages of transition involved parents as professional carers.
- III) The transition process remained flexible to parent's views throughout the process.

PARTICIPATION

Eleven consultations with parents during process.

OUTCOME

Review indicates a pro-active transition of service to the White Top Centre.

The consequence of the above approach should further develop professional/parent partnership within the White Top Centre.

Increasing our knowledge base through a holistic approach obviously creates more opportunities for our service users to aspire to achieve their unmet needs and desires, which hopefully facilitates increasing control over aspects of the person's life regardless of their present situation.

The future development and integration of different resources within our holistic framework will no doubt contribute to the debate concerning the appropriate treatment of carers within the social care system, thus influencing policy making bodies as to exactly what their relationships with carers are and should be.

It would be of interest if there are any Development Officers, parents or organisations who could offer some input towards our strategy development. Please feel free to contact me at the White Top Centre.

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THE PERIPHERAL PARENT;

Reflections on the Role of Fathers in Early Intervention

INTRODUCTION:

In 1990, a small investigation was carried out into the reaction of mothers to the fact that their newborn babies had been born with Down's Syndrome, and of their feelings and reactions in the weeks immediately following the births. These children were born in 1986-87, and they and their families were known to the researcher through her work as a member of a team of teachers devising intervention programmes for pre-school children with possible special educational needs. This work takes place in the home setting and aims to enhance the skills of both parents and children.

This small research project involved interviews with the mothers and hence, reflected only their feelings and their perceptions of the fathers' response. An increasing awareness developed of how little was known of the reactions of the fathers in these circumstances. This is an area which has been relatively ignored (*Meyer, 1986*), and the literature is sparse. Consequently, in 1991, the researcher decided to redress the balance a little and to investigate the feelings of the fathers of these same children at the time of their birth.

EARLY CONSIDERATIONS:

Before embarking on this in depth study, careful thought was given to the method of approaching the fathers and indeed, if the approach would intrude into areas of their lives which were wholly private. This concern arose because during the interviews with the mothers, some became very distressed when discussing the events of the early weeks, and it was felt that fathers may exhibit similar feelings and become embarrassed. Secondly, the mothers commented on the fathers inability to discuss the child with them. "He was very upset, he's never said much since".

After lengthy discussions with professional colleagues, it was decided to approach the fathers formally by letter - the wording of which would emphasize the academic aspect of the study and lack of information on the subject. It was hoped that as the researcher was known to the families, she would not be perceived as "a prying individual interested in research for its own sake"! (*A father-1991*). The letter included a tear off slip which the fathers were asked to return only if they were prepared to talk. Despite the initial fears, all seven were returned.

As the fathers were not accessible during the day, the interviews were arranged for the evenings (at around 8pm). This fact may account for the lack of information about fathers for as *Collins (cited Meyer, 1986)* points out, not many researchers like working at weekends and during the evenings - a time when fathers are available.

The interviews took place in the home and the responses were recorded in note form as it was felt that the presence of a tape recorder could have been intrusive. Both the length of the interviews (between 2 and 3 hours), and the apparent ease with which the fathers spoke, surprised and moved the researcher. This could be attributed to the fact that at last they felt someone was listening to them, (*Cunningham and Davis, 1985*).

Whilst it must be remembered that "talk of past emotions is distorted through selective perceptions and selective memories" (*Murgatroyd, 1985 p87*), the events surrounding the birth seemed particularly clear and matched almost exactly those of the mothers.

BREAKING THE NEWS:

The diagnosis will be the most disturbing crisis the parents will face during the child's life (*Wikler, 1984*), and in all seven cases it was the hospital Paediatrician who gave the news. Although there can be no optimal time to do this, there must be an optimal method (*Erikson, cited in McConachie 1986*). *Cunningham and colleagues at the Hester Adrian Centre have attempted to explore this and to formulate a preferred way of imparting the news.*

HOW WERE WE TOLD?

When the news was broken by the Paediatricians, the style of delivery varied from the "abrupt" to the "sympathetic and understanding:

"Within minutes, the Paediatrician was by our side. His eyes were full of sympathy, his voice soft and understanding; before he uttered a word we knew something was wrong. He told us in clear, unambiguous terms; "I think there is something wrong with your baby's back and lower limbs. I am sending her for further tests". His calmness contrasted the inner turmoil we began to feel. Helplessness descended upon us : my wife lying on the operating table following the Caesarian Section : me garbed in medical gowns".

THE RESPONSES:

Similarly, the responses portrayed "anger", "shock", disbelief", "numbness".....

"Shock was an inevitable response, but my male protector role came to the fore - "we can cope; this is fine. She is our baby; we have the experience.....". My next recollection was of some nurse reviving me on the operating room floor - I had fainted! At this point we were too numb to cry; we had to have hope : his (the Paediatrician's) diagnosis was incorrect; he was mistaken - he MUST be mistaken".

TOO MUCH - TOO SOON:

The issue of "how much" information and "when" was a recurring theme in all seven fathers interviewed for this study. The most unwanted information was often that of further complications, such as a heart defect.

"Inevitably we asked for more information than his initial bald description of the bare facts of our baby's disability. "Was it Spina Bifida?" "No" was his response. If anything, he thought it was Sacralagenesis. What was this? We had never heard of it? "And there are some complications with the baby's heart too". But I don't think I heard that comment at the time, I was still stuck on Sacra-whatever-it-is"!

CONTENT OF INFORMATION:

The professionals suggested a range of strategies through their advice, some suggested adoption, surgical intervention, or even putting the cot behind the bed "so you don't have to look at her". The fathers who felt the news had been given badly or were unhappy with these contacts, were deterred from complaining because, "the medical fraternity stick together", and were concerned that any action may have an effect on future contacts with the doctors on whom they may be dependent for ongoing care.

"At every step we were kept informed. They told us when they were carrying out tests, and what the test results were as soon as they were known. But it seemed like an eternity between the two. We were so anxious, and all the time the feeling of helplessness persisted, disabling us from answering even the simplest of questions like "would you like a cup to tea". When we did summon up the mental energies to ask questions, we were given honest answers. I say 'we', in fact I would creep out of the side ward we had been placed in to find a passing nurse or doctor who might have some more news. I did not want them to tell my wife, to increase her distress, I wanted to bear it all".

PROFESSIONAL PERCEPTION OF FATHER:

The fathers felt that because they were regarded as "different", the hospital staff were not trained to deal with them. They were constantly watching for others' reactions conveyed by words and body language.

"A nurse constantly attended my wife, and gave me kindly glances. Any medic who came anywhere near our room must know something, and I pounced upon each of them. When there was news to give, they told us together, but all the time you expected more. Were they withholding information"?

PROFESSIONAL PREDICTION:

Many contacts, medical and social, offered gloomy forecasts of the effects the child would have on family life. A General Practitioner warned that the mother may become "mentally unstable and may attempt suicide or harm the baby". Another was warned his marriage would fail.

"This must all be a dream" – this thought ran through my mind again and again. This cannot happen to us! In this turmoil I was conscious of the supportive attitude of the hospital staff, and that every effort they made was an endeavour to uphold us, to help us to endure the pain and distress that fell upon us as the reality of our baby's disability dawned upon us".

INFORMATION SEEKING:

In all cases, fathers sought additional information initially from books, but later, from other families and professionals

"In spite of what we had been told by the Paediatrician, it was not enough. A thirst for a greater and a deeper knowledge became all-consuming. This search became a driving passion. I wrote to anyone and everyone who may be able to throw more light on our baby's disability. When I finally made contact with an appropriate parent support group, I scoured their membership lists for other parents nearby who had similar children. Once I realised that we were but the only family in the area with this type of child, I accepted, with a degree of peace, the knowledge I had gained".

NETWORKING:

Hornby (1991) recommends networking amongst families. Various practical examples of this exist (Carpenter and Carpenter, 1989). In the context of this small scale research, the sensitivity of this process was highlighted. Whilst acknowledging its implicit value, it was found that families needed more than "one feature in common" (Byrne, Cunningham and Sloper, 1988) in order to make the contact positive and effective.

"As in any set of personal relationships there are those that are richer and more rewarding than others. With some families, our only point in common was that our children had the same disability, and this led to a fairly factual exchange of information; but even that was helpful. With other families, there were interests in common other than our children, and time spent with these families was for the same reasons one might spend time with any set of friends. What is unique about friendship with other families is the depth of understanding : they are more than the sincere, empathetic professional. They have been there too - through the endless hospital appointments, the perplexing behaviour patterns, the unanswered questions. This in no way diminishes the invaluable contribution of professionals, but to live with a child with a disability 24 hours a day, brings lessons that no professional course of training can ever hope to teach".

SOURCES OF SUPPORT:

Extended families were found to be a major source of support to the fathers. It could be conjectured that the existing familiarity at an emotional level with other family members generated a climate of openness in which fathers could reveal their true feelings.

"Is it the child that remains in each of us that causes us to turn to our own parents in times of despair? Certainly, the unquestioning support of members of our extended family helped greatly with establishing the valued place of our disabled child in our family. Their capacity for support is endless : is it duty? Is it love? Whatever the reason, the emotional dialogue we have with our extended family has at times been our salvation".

THE CALM AFTER THE STORM:

When the family returned from the hospital, the fathers reported that no help was offered specifically to them by the professionals. Any help was focussed on the wife and baby. The fathers' needs were not addressed or perhaps even noticed, all being seen as "the supporter" and adopting the role society expects that of being competent in a crisis (Tolston, 1977).

"Having been on hand at the hospital to receive all of the necessary information first hand, my frustration began to mount at having to receive all information via my wife, as I had returned to work. The telephone would ring and the professional would ask to speak to my wife; all appointments were made for my wife to attend (although the offer was occasionally made that I should attend, it was often impractical to do so). I accepted much of this, but just once in a while it would have been wonderful if one of the many professionals we were dealing with had offered to call one evening so that I could have actively engaged in the dialogue of care for our child. What gradually happened was that I, as the father, became, in

some ways, 'disabled' also in the supportive role I was expected to fulfil. Although my wife recalled conversations with professionals as accurately as possible, there was inevitably something that she had omitted to ask, or that they had not explained fully enough. But it is hard with a struggling baby on your lap to totally concentrate, and articulate your thoughts. My frustration grew at never being part of the interaction with professionals who were playing such a major part in my child's life, and to some degree influencing the direction and shape of our family life".

SEARCHING FOR NORMALITY:

All seven talked of returning to work and on trying to keep a "sense of reality in our lives".

"I returned to work, but in a fog. The feelings of disorientation were enormous and even simple tasks took considerable effort to complete. This only served to disempower me even further.

What was needed was a time of reflection; to consider how our lives might develop. Old routines may no longer be totally appropriate. I remember feeling constantly tired, and when I did sleep it was very deeply, but, paradoxically, it was not refreshing."

PLANNING FOR THE FUTURE:

Although this may be seen as a need for "normality", it can be viewed as an escape from the situation at home. Perhaps if more effort was directed towards the fathers in these early days, it would enable them to explore and formulate strategies to cope with future crises. They were aware of their need to talk to someone and perhaps for a third party to help out with their wives, but no one fulfilled, or fulfills, this role.

"At the end of the day only you, as the parents, can make the ultimate decisions. But in those early days, this was a mammoth task. With levels of concern about our child so high, combined with tiredness, and the routines of caring for other family members, the quality of decision-making was far from what it ought to have been. In spite of the care of family and friends, the support of various professionals, the experience of having a disabled child can, in the early days, be very isolating. All either partner wants is the other. This child was created out of your love for each other, a product of your union. That same love must now help to reformulate what you had anticipated for your family whilst absorbing the pain and the grief. What the family unit needs most during its phase of re-adjustment is to feel safe and secure; that there are people around - friends, family, professionals, holding you together, enabling you to exist. And at times, it is existence, not living".

PROFESSIONAL ACCESS:

One reason for this issue may be that the majority of support services work only during the day when many fathers are at work, and after the first few days, all such contacts took place during the day and therefore, all information reached them second hand with the changes inherent in the retelling and giving the mothers' construction of events.

"What did they say?" To this day, following every appointment that is the question I ask my wife. Always it is tinged with anxiety; always anticipating the worst. And I expect an immediate answer, a full blow by blow account. It doesn't matter if the evening meal is just ready for serving; now it must be! I have tried saying this question in various ways - calmly, with a smile, from another room in a casual, semi-interested way - but inevitably my deep-rooted anxiety comes through! Invariably, I will follow up my wife's account with "And did you ask about.....?" Either she did, and the answer was unsatisfactory, or she did not - in which case she feels guilty because she failed in her imposed role as our envoy. Is this really a healthy state of affairs? Does it act in a supportive way to the family of a child with a disability? Does it not create tension, disempower the father, cause the mother to feel inadequate? What was the overall value to that family of the professional interview? Has it really acted as a catalyst for strengthening that family's resolve to care more effectively for their child? Was it a growth point?

As yet, my answers to these questions would tilt towards the negative. But then I am only the father; the secondary partner".

CONCLUSIONS:

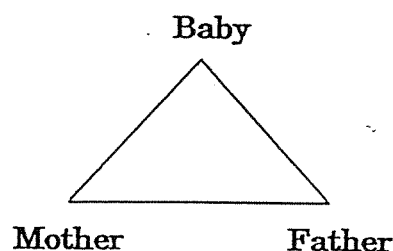
An overwhelming question throughout this study, was that of professional accessibility at all stages of the journey parents make following the birth of their child with a disability. For fathers, this is an unresolved issue because it is assumed that the ongoing dialogue can be sustained in the main through the mother.

Is this fair to fathers?

Are we meeting their needs?

Are we being professional in our response to them?

Whilst professionals like researchers prefer not to work unsocial hours, we must look at the triad



and not solely at the dyad of mother and baby and adapt our support services to fit the needs of the whole family, for at present, fathers are, unfortunately, the secondary partners.

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Four Good Legs

The Diamond Riding Centre For Handicapped Riders
Woodmansterne Road, Carshalton, Surrey, SM5 4DT

It was in 1959 when I first saw a handicapped child riding a pony. I was impressed at seeing the empty wheelchair left behind in the stable yard as she went off riding along the hedgerows and bridle paths. Other than that I gave little thought to the matter subsequently. Until in 1969 I was asked to undertake a pilot scheme at Queen Mary's Hospital for children, Carshalton, Surrey. The purpose of which was to explore the benefits that might be derived by patients riding.

Six riders were chosen, three mentally handicapped and three physically disabled. The scheme was scrapped within a matter of weeks! The benefits were so obvious that other staff clamoured for their patients to have the opportunity to ride too. For the rest of the summer sixty children from the hospital rode until the chill of the autumn mists brought the sessions to an end.

My greatest fears were that those who had helped would soon forget during the winter months and they would go on to do other things. The riders did not forget though. As I entered a ward during the bitter weather of the following March, a little severely mentally handicapped child rushed up and hugged me round the knees and excitedly shouted "Horsy! Horsy! Horsy!"

Our early success encouraged us to commit ourselves to provide riding for disabled people in South London and the surrounding area. Such a service has to be able to continue regardless of season or weather. Thus the Diamond Centre for Handicapped Riders was built. At the present time the Centre caters for some five hundred riders a week throughout the year.

The Diamond Centre was opened by The Princess Royal in 1974. Since then the Centre's sustained success and growing International reputation has been evident to all. If we are not to hold out false hopes to too many others in large urban areas, then more centres that can meet their expectations must be built. The same must apply world wide if riding is as important as some would claim.

Why should handicapped people ride? The first thing you and I notice is their disability. Many people do not get beyond that barrier. Riding a pony makes the rider, their carers and everyone else, aware of their abilities. Besides looking down on you for a change, you are having to look up to them both physically and socially.

Riding a pony gives them the opportunity for non-verbal communication and an outlet for emotional expression. The experience of stroking the warm soft coat of a gentle but undeniably powerful animal is unforgettable. The pony accepts them as they are and does not make patronising concessions for their disability.

The freedom of movement that the pony gives brings the freedom of physical expression denied to many of them. The will to achieve more than

they thought possible is stimulated in most riders. They, their physiotherapists, instructors and helpers can move mountains together. Imagine, the freedom of movement that the pony gives to a blind person.

The pony is a bridge whereby those children who have anti-social behaviour problems or who are withdrawn, can be reached. The standards of social behaviour expected by the adult world can be taught through the pony. Socially acceptable behaviour is the easiest path to being accepted as a person.

What is the relevance of riding in a world of such deprivation? Is it obscene to spend money on riding when there are so many people starving in the world? Will any of us, more fortunate, give up our recreation because of all that is wrong. We take for granted that such pursuits will enable us to cope better in our own lives. What is a luxury for most of us, can be a necessity for others.

Joanne's disability was such that she was affectionately known as "Rag Doll". On a pony she flopped about even more. As the years went by none of us realised that she was developing her trunk muscles that were important to do something that you and I take for granted, but we do every day without any thought. Now, as she is growing up, she is able to sit unaided on the toilet and maintain some human dignity. Handicapped people are not objects to be put where we think and to have done to them what we decide.

John is a Cerebral Palsied adult who, when a child his behaviour had been such, his father alleged, that it had driven his mother to commit suicide. Upon total rejection by the father, this small, sensitive child was taken into care by the Local Authority, increasing his sense of isolation. He withdrew even further beyond the reach of those who were desperately trying to help him. Because he was known to love animals, he was asked if he would like to ride a pony. So began the long road back to reality.

This slight figure of a boy rode before a large crowd at one of the Centre's Open Days. Of course he would only ride the biggest and most powerful of the ponies. The others were not enough of a challenge for him by then. You could have heard a pin drop as he and his pony cleared jumps that many would have refused. At one point he got into difficulties. He was beginning to lose his balance, the pony side stepped catching the child on balance, steadied and then they both took the last jump in great style. The cheers that broke out nearly took the roof off. The applause would have been envied by any International Show Jumper.

Kim is a Down's syndrome grown up who as a child had no liking for ponies and made it quite clear she had no intention of co-operating when it came to being put on one. For several weeks she anticipated the intention and she was evidently ready and very able to repel any one foolhardy enough to try. During the weeks that passed she would walk up to the pony hand in hand with her helper. She would stand and look at it. She would walk around it. No attempt would be made to put her on it. Hand in hand they would walk away from it. As the weeks passed Kim began to give her helper some odd looks and was beginning to have more misgivings about her helper rather than the pony.

She was no doubt relieved when it was suggested the following week, that her brother came and looked at the pony too. On reaching the pony, without a word her brother was put up on the pony. This was too much for Kim. She demanded to join her brother on the pony and then pushed him off. She was not prepared to share "one-upmanship" with anyone, even her brother. When other children had taunted her brothers at school about their sister, they were able to say with pride. "She rides a Pony!" She has over the years become a very self-assured rider and a very outward going young lady. She has the social graces to hold her own.

Unfortunately Paul is so severely mentally handicapped that little seemed meaningful but he received a Proficiency Certificate. What it stated, was true. "Paul has ridden for five years and loves his pony very much". His Mother broke down in tears. Subsequently she explained, after drying her eyes and blowing her nose, no-one had ever taken any account of Paul but now someone was prepared to declare to the world, in writing, his ability to Love.

We are frustrated by our own inability to communicate with deaf people. Imagine their frustrations, their loneliness in a world where silence is either total or one of meaningless distorted noises. Physical communication is the most direct and the least misunderstood means of communication of all.

On a pony, suddenly they are no longer alone. Through your hand, legs, the whole body and even the soles of your feet you can communicate your joy, your sorrow and your love. The pony communicates too with every muscle and every fibre of his body. The rider and pony respond to one another in an orchestration of physical music. There is no reason why a deaf rider should not compete on equal terms with able bodied riders up to and including International Equestrian Standards. It will be their instructors who are handicapped.

Claire was 13 years old when she started to ride. Her condition was terminal cancer. A once active child was reduced to lying on a sofa for most of the day. She was not prepared to wait for death. It would have to come and find her. She rode several times a week but her active mind also had to be challenged. She set about studying the care and management of ponies, their training and riding theory. Her essays and the answers to the examination papers that were set for her by the centre's staff showed a profound and mature understanding of the subject.

Her practical tests were an ordeal for everyone, for to pass them on anything but merit, would have been an insult to her intelligence. In the event of failure there was no time to take the exams again as time was running out. Her pony made sure she passed, with flying colours.

Eventually, Claire was admitted to hospital for the last time. During her brief periods of consciousness the telephone would ring at the centre and her pony would set out for the ward. The natural warm smell of that pony would overwhelm the clinical atmosphere of the ward as he peered curiously through the raised sash window. The bed faced towards the window so that she could see him. When she died she was very happy.

Her room was full of ponies; cards, pictures, models and ornaments. If there are any tears to shed then they are for us who are left behind. We are the ones who have to come to terms with the harsh realities of our world.

Riding a pony can help soften the cruel blow fate has dealt those who are handicapped and help them to overcome their defeat, their despair and their sense of failure as they see those younger than themselves become so effortlessly more able than themselves. Riding gives them a sense of achievement, self-respect, self-confidence and an essential sense of self-reliance.

Fortunately the human spirit can overcome any adversity if given the chance and encouragement. If handicapped people are to take their rightful place in society, they will do so more readily if they are able to give of themselves. Knowing their own capabilities is the first step. If two legs cannot get them there, then the four good legs of the DIAMOND PONY will.

THE MENCAP PIMD SECTION - A NATIONAL SERVICE SUPPORTING PARENTS/CARERS OF PEOPLE WITH PROFOUND AND MULTIPLE DISABILITIES

On Friday, 24th June, during MENCAP week, the PIMD Section is launching the publication of the first of a series of 3-day workshop training packages for parents and carers of children and adults who have profound and multiple disabilities. This package, called **The Development of Early Communication and Feeding**, is the culmination of several year's research, including a survey into the needs of parents and carers of people who have profound and multiple disabilities. Further details about the survey can be obtained from the PIMD Section (Hogg and Lambe 1988).

In setting up the PIMD Section and undertaking the survey, MENCAP made a commitment to these families. It was recognised that parents and carers had a wealth of knowledge and experience in caring for and supporting their daughter's or son's development. However, it was also apparent that these families needed additional assistance due to the demands of caring for someone with profound and multiple disabilities, e.g. the large proportion of time spent in attending to personal needs or the apparent difficulties in communicating.

It was the parents and carers themselves who identified the areas where they felt they needed additional help and support (from the survey) and MENCAP responded by offering practical assistance in the form of 3-day workshops in each of the topics identified by them. In addition to the Development of Early Communication and Feeding, the other topics were:

- Physical Management
- Management of Difficult Behaviours
- Dental Care and Healthy Eating
- Planning for Leisure
- Planning for the Future - Wills, Trusts and Residential Provision
- Rights and Entitlements - Understanding Benefits and Allowances

These workshops were piloted and evaluated in Manchester and it is from this model that the workshop training packages are being developed. All the packages will be of a similar format consisting of a ring binder containing three distinct sessions. The first of these is an administrator's section which deals with the practical aspects of administering such a workshop. The second section contains all the information the tutor will need to enable them to put on the workshop in the relevant topic, including the programme, aims and objectives, content and supporting visual aids. The final section contains instructions and materials for compiling an information pack for each participant.

The workshops were offered to parents and carers free of charge, transport was provided where necessary and leisure provision was also made for available for their daughters and sons (with and without disabilities), so that they did not have to worry about respite care while they attended. One development of the latter provision has been the continued demand for specialist summer play/leisure schemes for children and young adults who have profound and multiple disabilities. The PIMD Section now offers places to approximately 100 young people of school age in Manchester, during the summer holidays. These schemes provide enjoyable activities and play/leisure opportunities for those who attend and also essential respite for their families.

It is clear that there is an increasing demand for this type of provision and an information pack on organising and running a similar specialist play/leisure scheme is being developed to enable statutory and voluntary organisations elsewhere to develop something similar.

Professionals who have both the relevant experience in the topics identified and considerable understanding of the needs of people with profound and multiple disabilities, will be able to use these packages to provide support where it is needed by running similar 3-day workshops. It is intended that parents and carers in other parts of the UK (and beyond) will benefit from the dissemination of the information in this way. The package will, therefore be of value to schools, day services,

hospitals and any other statutory or voluntary organisations offering services to people who have profound and multiple disabilities. Similar workshops can also provide valuable training for new or inexperienced professionals in the field.

A 'flyer' for this workshop training package is enclosed with this issue of PMLD Link, and a 'Training the Trainers' Day will be run in Manchester on Friday 25th November.

The Development of Early Communication and Feeding:

The Tutor's section of this package discusses, in detail, how communication develops from birth, the reasons why we communicate, what we communicate, how we communicate and the conditions that are necessary for communication to take place. It also identifies the development of 'normal' eating and drinking patterns, some of the difficulties encountered by children and adults who have profound and multiple disabilities and suggestions for how some of these difficulties may be remediated or minimised.

Recommendations are made about the potential disciplines from which tutors may be identified, but because of the Feeding component of this workshop it is essential that at least one tutor is a qualified Speech and Language Therapist. The Communication component may be undertaken by a Speech and Language Therapist also, but could be a teacher, psychologist, nurse for example.

The administrator's section for all the packages contains information on organising the workshop, e.g. identifying participants and tutors, securing the venue, transport, catering, funding, etc., in addition to information specific to each workshop topic.

The participant's section provides a list of all materials that should be made into an information pack for those who attend the 3-day workshop. This includes one copy of each handout/worksheet, etc., which is not subject to copyright restrictions when used for the purpose of the workshop.

An Information Service:

The PIMD Section also has a reference library and computer data base on all aspects of profound and multiple disabilities and welcomes enquiries from parents, carers and interested professionals. The co-ordinator also undertakes in-service training sessions by negotiation.

For further information about the workshop training packages, the 'Training the Trainers' Day in November, the information pack on organising a specialist play/leisure scheme, or any other aspect of the service provided by the PIMD Section, please contact:

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TRAINING: COURSES/CONFERENCES

JULY

- 13th and 27th Developing and Running a Horticultural Therapy Programme
(Split 2 day course)
Horticultural Therapy's short courses provide an introduction to horticulture as therapy, offering ideas and advice for those wishing to set up a new project or expand an existing project.
Venue: Chequers AEC, Islington, London

SEPTEMBER

- 5th to 7th International Conference on Developments in Sherborne Teaching
The conference will focus on research and developments in Sherborne work over recent years in a variety of contexts. International and nationally known speakers to be announced.
Further details from John Dibbo or Sue Gerry, Faculty of Arts & Education, University of Plymouth, Douglas Avenue, Exmouth EX8 2AT
Tel. 0395 255397/255343
- 22nd PLANET Focus Open Day
For Therapists
Further details from Planet, Harperbury, Harper Lane, Radlett, Herts WD7 9HQ Tel: 0932 854861 Ext.4384

OCTOBER

- 6th CONFERENCE on Movement and Mobility for Children who are Multi-disabled and Visually Impaired organised by VITAL, an RNIB/VIEW Curriculum Group.
Venue: Condover Hall School
Further information from Jonathan Griffiths, Cruciform House, RNIB Condover Hall School, Condover, Shrewsbury, SY5 7AH Fax and Tel: 0743 873459
- 13th Supporting Children with Multi-sensory Impairments
This three day course for care-workers and special needs support assistants working with multisensory impaired children will be delivered in three individual day sessions spread over the Autumn and Spring terms
Further information from Olga Miller, Inset Co-ordinator Tel. 081-1968-8600 or 071 612-6277
- 15th PMLD CONFERENCE - Promoting Quality of Life for People with Profound and Multiple Learning Disabilities
The programme will cover pre-school; school years; transition to adult services and further and continuing education. The conference will bring together practitioners and researchers working in all these areas to share their experiences and findings with the aim of improving policies and practice for all learners with profound and multiple disabilities.
Venue: University of Birmingham
Further information from Loretto Lambe, The White Top Research Unit, University of Dundee, Dundee DD4 1HN

27th Mobility Training for Visually Impaired Children in the Pre-school and Early Years
Workshop aimed at parents, teachers and support assistants working with young visually impaired children or older children with learning difficulties
Further information from Olga Miller, Inset Co-ordinator Tel. 081-968-8600 or 071-612-6277

NOVEMBER

22nd PLANET Focus Open Day
For Advice Workers and Information Officers
Details from Planet, as above

NEW BOOKS

Creating A Responsive Environment for People with Profound and Multiple Learning Difficulties by Jean Ware - Routledge and Keegan Paul (in press - due August 1994)

Implementing the Whole Curriculum for Pupils with Learning Difficulties edited by Richard Rose, Ann Fergusson, Caroline Coles, Richard Byers and David Banes - Fulton

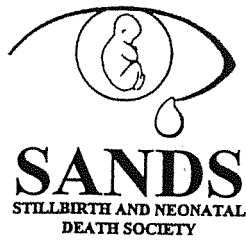
Learning for Life: A pack to support learning opportunities for adults who have profound intellectual and multiple physical disabilities produced by MENCAP and FEU available from the Further Education Unit, Citadel Place, Tinworth Street, London SE11 5EH

Taking Control: Enabling People with Learning Difficulties edited by Judith Coupe O'Kane and Beryl Smith - Fulton

Educating Children With Profound and Multiple Learning Difficulties edited by Jean Ware - Fulton (in press - due August 1994)

Objects of Reference - Promoting Concept Development and Communication Skills with Visually Impaired Children who have Learning Difficulties by A. Ockelford - RNIB

Space and Self by Lilli Nielsen - RNIB



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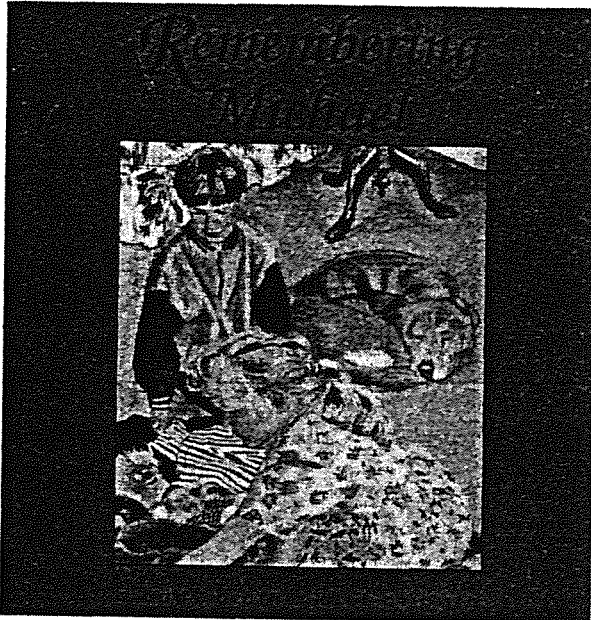
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REMEMBERING MICHAEL" by Anita Harper (ISBN 1- 869903 - 21 - 8 £6.95)

34 pages with illustrations by Helen Averley



The SANDS Children's book "**Remembering Michael**" is based on the experiences of many parents and children who talked to the author and psychotherapist Anita Harper. She says: "there is actually very little in the book that isn't somebody's experience although the characters and the story are fictional."

Anita was delighted to write it because she believes that children have a hard time getting heard. For parents immersed in their own grief after the death of a new baby, the task of being there with their other children, with all their feelings, demands and questions can seem almost impossible.

Everyday in the UK 20 babies are stillborn or die shortly after birth. For the parents, the grief is hard to bear. For their children, it can be even harder. They look forward to having a new baby brother or sister. Instead their parents come home empty handed, unable to explain what has happened. Children find it difficult to understand their own feelings of anger, hurt and bewilderment.

To help them SANDS commissioned "**Remembering Michael**", a storybook for children which will help them realise that they are not the only ones who have had a baby brother or sister who has died. It is a book that parents have asked for, to help them support their children through this difficult time.

Order Form

"Remembering Michael"

To: SANDS, 28 Portland Place, London W1N 4DE

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..... copies @ **£6.95** £.....

UK postage & packing per copy @ **£1.00** £.....

Overseas postage & packing per copy @ **£2.00** £.....

Donation to SANDS £.....

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Please make cheque payable to SANDS

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Pear Tree Tomorrow.

A detailed video cassette about the dance movement therapy work carried out by pupils at Meldreth Manor School under the direction of Hilary Barratt.

Meldreth Manor School (1993) £48.00

This video tells the story of six pupils with profound and multiple disabilities experiencing a series of dance movement therapy sessions. The video, ambitiously, sets out to give a theoretical foundation for the work, an analysis of practice and an insight into potential outcomes. It begins with a definition of the purpose of dance movement therapy and a description of the part it plays in the multi-disciplinary team approach to the twenty-four hour curriculum followed at Meldreth Manor School.

The second section contains the theory. Over footage of pupils removing their splints and boots and coming out of their wheelchairs, a voice-over offers some rather elaborate, jargon-laden explanation. At strategic moments, ideas are more usefully summarised in static captions noting 'Action', 'Aims' and 'Pupils may experience' - broadly 'what we do', 'why we do it' and 'what may happen'.

The third section is what this video is really about. It follows the group of pupils through the whole of their seven month course of sessions and lingers, enthrallingly, on the action. Hilary Barratt herself provides a clear, purposeful commentary. She illuminates the processes unfolding on the screen with insights which emphasise pupil initiation, exploration and creativity. This section of the video reveals, in telling detail, what dance movement therapy can offer.

Who should buy this video? It will provide inspirational material for teachers, therapists, assistants, parents and others working with pupils with profound and multiple disabilities. But, inevitably, it cannot be seen as a real training in dance movement therapy techniques. It is more of an appetite whetter and, as such, it is very effective. Especially when, in the conclusion, Hilary Barratt sums up the positive outcomes of the sessions. This summary is then echoed by a teacher who says that Hilary Barratt's work has helped her pupils "to express their feelings and me to understand". Testimony indeed to the significance of the work which this video vividly brings to life.

Richard Byers. February 1994.

Subscription Year 1994/95

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