PMLD LINK

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Bulletin No. 16

CONTENTS

EDITORIAL

PMLD-Link is now 5 years old and, we hope, is 'growing up' into the kind of Bulletin that you want.

In his editorial for the last issue, Barry wrote of the beginnings of PMLD-Link, and how it has developed over the last five years. We now have an active editorial team - Barry Carpenter, Christina Tilstone, Loretto Lambe and myself - who meet once a term to discuss the current issue and future directions. We wonder what you, the readers and contributors, like about the newsletter. What inspires you to write in? Do you like the "grass roots" feel which we have tried to maintain, or would you prefer a more professional Bulletin? We have been discussing the front page layout. What do you think about putting the contents on the front? Does this help you to find what you want? We will be trying out a number of different front page styles so do write in and let us know what you think of them.

The editorial team has also been asking people to be regional contacts, to promote the newsletter in their own area and to encourage people to write in about their work. We hope to have a network of regional contacts throughout the whole country - including Scotland and Ireland, and perhaps even further afield eventually!

We hope that these new directions will increase the success of the newsletter in its primary aim to help people to keep in touch with other people, and to share good ideas and exchange information about new approaches and resources for people working with and caring for people with PMLD. PMLD-Link is about communicating with each other as a source of support and an impetus to moving forward in our work.

The focus for this issue is on Rare Syndromes - how to find out about what they may mean to a child and a family, and about organizations which help people, carers in particular but also other people involved, to link up and provide support to each other - communication again.

If we need communication as a means of gaining support, finding and giving information, and exchanging ideas, so too do our children, pupils, students, clients or users of the services we provide.

The next issue, due out in the Autumn, will be focusing on communication for and with people with PMLD. It is of such fundamental importance to us all that we hope this will be a bumper issue. I am sure there is no-one who has not spent many hours thinking of ways and means to establish, or build upon the two way communication process. If you have any ideas, questions, thoughts on the subject - write in. It can be a short paragraph or a (not too long) article, but don't forget

... PMLD-Link depends on YOU communicating with US!

Carol Ouvry

FOOTNOTE:-

Barry Carpenter has been appointed to the post of Senior Tutor to Westminster College, Oxford, with specific responsibility for school-based initial teacher training.

He will continue to serve on the Editorial Team of 'PMLD Link', and to undertake in-service training throughout the UK in the field of Special Education.

BUSINESS MATTERS - or Further Communications!

SUBSCRIPTIONS 1993/94 - Reluctantly we have had to increase the subscriptions for PMLD-Link for 1993/94 and the new amount is 6.00 for the year. THis is still subsidised, but does help to cover more of the cost of producing and mailing it to you. ALL subscriptions are due in September, so please subscribe as soon as possible (unless you have already done so) as this will ensure that you will not be deleted from the mailout because your subscription is late.

AUTUMN ISSUE - Items for the next issue should reach me by 1st November. This gives those of you who are in schools the half term in which to dash off something at the last minute, and me time (just) to collate and organize printing and mailing before Christmas. Please could you send articles typed in single line spacing if at all possible. As you will realise, articles are very rarely edited, and are usually put in just as they are received.

FUTURE FOCUS - If there is any issue which you would particularly like us to focus upon in future issues, please let us know. PMLD-Link is for you, and without your comments and suggestions we are just guessing what may be of importance and interest to you.

Finally, the editorial team thank all of you who have written for this issue and we wish everyone a very pleasant summer break.

Carol Ouvry

EDITORIAL POSTSCRIPT

Since the Editorial I wrote for issue 15 (Spring 1993) of 'PMLD Link' several people have asked how my wife and I went about finding out more about Sacralagenesis, the disability from which our daughter, Eleanor suffered.

In the past, I had found the 'In-Touch' organisation run by Ann Worthington, a very good source of information about rare syndromes. Often, through her contacts, I have been able to network other parent support groups, or locate a specialist source for parents. Sure enough, Ann could help this time. She had some clinical descriptions of Sacralagenesis; that the incidence was 1:10,000; that it was more common in diabetic mothers, (a painful fact for my wife to bear, as she is diabetic); that it was part of a wider syndrome crudely known as the 'Mermaid Syndrome', (it was several months before I could tell my wife this). 'In-Touch' also provided us with the address of the National Parent Support Group.

This was hard to bear: some children with this disability live, but ours, whose face radiated the most magnificent beauty, had died. Still we wrote. There were only 18 sets of parents in the group: half of the mothers were diabetic. The children had varying degrees of Sacralagenesis, just as there are varying degrees in any disability.

Our personal quest for information stopped there. We did not join the Sacralagenesis Parent Support Group; there seemed little point. My wife has since corresponded, through the British Diabetic Association magazine "Balance", with four mothers who have gone through a similar experience. One of these mothers has successfully had another baby since her Sacralagenesis child (who also died). This gave a glimmer of hope. After reading Susan Hill's powerful book "Family", that hope became a reality.

On March 9 this year our daughter, Grace Susan, was born. She is a perfect, healthy baby, who, at birth, was the image of her sister, Eleanor. But Grace is not a replacement for Eleanor (who taught this family so much). Rather she is a manifestation of that love which is Eleanor; a powerful love which continues to influence our lives, for in plummeting the depths of grief we, paradoxically, soared the unknown heights of love as a family.

Barry Carpenter
May 1993

REFERENCE:

Hill, S. (1989) Family

London: Penguin Books

USEFUL ADDRESSES:

British Diabetic Association, 10 Queen Anne Street, London

WIM OBD. Tel: 071 323 1531

(the BDA produces a range of useful information for diabetics and about diabetes. They have packs especially designed for children).

'In Touch' c/o Ann Worthington, MBE, 10 Norman Road, Sale, Cheshire, M33 3DF
Tel: 061 962 4441.

SANDS Stillbirth and Neonatal Death Society, 28 Portland Place, London, W1N 4DE. Tel: 071 436 5881.

(SANDS Produce some excellent supportive literature for bereaved parents, siblings and grandparents).

BIBLIOGRAPHY:-

Stopford V (1987) Understanding Disability: causes, characteristics, and coping.

London: Edward Arnold

Lewis V (1987) Development and Handicap

Oxford: Basil Blackwell

IN TOUCH

Information and Contacts for Parents of Children with Special Needs

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Recent years have seen a change in the attitude of parents of children who have special needs. Many are no longer content to be left in ignorance about the nature of their child's condition, but wish to find out all they can about it, to understand its implications and, if possible, share their experiences with others who have a similarly affected child. Progress in diagnostic techniques is enabling doctors to put a specific name to many more disorders where, previously, parents were simply left with a diagnosis of 'handicap of unknown cause'.

IN TOUCH was founded, twenty-five years ago, by Ann Worthington to bring together parents of children with the same kinds of special needs. The aim was to relieve their sense of isolation and meet their need for practical help, by providing them with the opportunity to share their experiences and ideas with others in a similar situation. IN TOUCH seemed to enter the field at this time of growing awareness and there was an immediate and enthusiastic response from parents all over the country, indicating that there was a real need for this kind of personal communication.

IN TOUCH began as a mental handicap service, but has widened in scope to cater for all types of special needs in children; educational, physical or a combination of both. The organisation is able to direct parents to sources of advice on all aspects of coping with disability; special educational needs, respite and residential care, aids and equipment, financial advice, behavioural problems, etc. They are presented daily with queries about uncommon (sometimes extremely rare) disorders and have built up a large bank of reference material. This enables them to identify most conditions and to recognise, from its main features, which support organisations will be able to offer the most appropriate help.

From the beginning, IN TOUCH grew of its own accord, with no positive attempt to seek publicity. Year by year, the number of enquiries and the membership grows steadily. Now they receive some 3,000 enquiries each year, and around 1,400 members receive a newsletter every four months. The demand for contact between parent of children with rare disorders has become so great that it constitutes a large part of the work of IN TOUCH. In the case of some rare conditions, parents have gone on to act a co-ordinators of contact or self-help groups. Some of these have remained small and informal, others have developed into efficiently structured national associations.

Parents come in various ways; at the suggestion of their health visitor, social worker, paediatrician, etc. or via organisations such as Mencap, Contact a Family or Barnardo's.

Most get in touch because they have just been told that their child has a specific rare handicap, about which they may know very little. Because their condition is rare, there is little likelihood of their meeting other parents whose child has exactly the same set of problems. They may feel confused, fearful for the future and very isolated, and their most immediate need is for the opportunity to talk to someone else who has a real understanding of the condition, its management and its implications for the future. One of the main aims of IN TOUCH is to provide practical information as to further sources of help, but this is only part of the service. It is of equal importance to provide as much reassurance and friendly encouragement as possible.

Professionals now make up about one third of the membership and include doctors, social workers, health visitors, psychologists, teachers and therapists. Many of the daily enquiries come from professionals on behalf of families with whom they are working. They cannot offer medical advice, have a comprehensive library on rare disorders and will provide information to professionals, so that they can be fully informed about the child's condition.

IN TOUCH has an arrangement of reciprocal membership with most of the major organizations in the field of childhood handicap. This results in a very effective network of combined expertise and enables them to confer with each other whenever IN TOUCH is presented with an unusual or difficult enquiry. There are times when several organisations work together over a period of days of weeks, in order to find the right kind of help for a particular family, often with the most rewarding result.

The IN TOUCH office is based at the organiser's home, and because they do not hold large conferences and because the work is essentially personal and confidential, it is difficult to demonstrate its results. Where a family's ability to cope with their problems has been transformed by being able to share experiences with others or by finding a source of positive educational or medical treatment, the benefits are known only to themselves and to IN TOUCH - and that is the way they feel it should be.

In 1985, Ann Worthington was awarded the MBE, in recognition of her work as founder and organiser of IN TOUCH.

The future of IN TOUCH depends upon being able to find funds to continue the work. No charge is made to those seeking information on a once-only basis. A newsletter is sent out to approximately 1,400 members, three times a year. Those who wish to receive the newsletter and to use the information service on a regular basis may do so by registering as a member of IN TOUCH. The annual subscription is 5.00 (optional) for parents of handicapped children and 10.00 for professionals and organizations.

CONTACTS WANTED : MISCELLANEOUS DISORDERS

Where a condition is known by more than one name, the alternatives are also listed. ** *Contact group exists* > *Indicates new entry*

Aaskogg ** (USA)
Aicardi **
Amyoplasia
Aneuploidy
Angelman **
Arterial calcification of infancy
Arthrogryposis **
Asperger **
Asymmetric crying face
+ cardiac defect
Ataxia telangiectasia **
Atkins >
Beckwith – Weidemann **
Binder
Blackfan – Diamond **
'Bobble – headed doll'
Cayler
Cerebellar ataxia/aniridia >
Charcot – Marie Tooth **
CHARGE Association **
Cholesteatoma + Downs
Chorea, congenital > (adult)
Chronic granulomatous diseases **
Cleidocranial dysostosis
Cloverleaf skull **
Cockayne **
Coffin – Lowry **
Colomboma **
Cornelia de Lange **
Corpus callosum, absent **
Cri du Chat **
Cyclical vomiting **
Cytomegalovirus **
Dandy – Walker ** (USA)
Dermatomyositis **
Edwards (trisomy 13) **
Ehlers – Danlos **
Elective mutism ** (USA)
Ellis van Creveld **
Encephalitis **
Encephalocele
occipital
Epidermolysis hyperkeroderma
Erb's palsy **
Escobar
Evan's ** (USA)
Foetal alcohol syndrome
Floating harbour **
Fragile X **
Frontonasal dysplasia
Gillespie >
Glanzmann thromboasthenia **
Goldenhar **
Gonadotrophin deficiency >
Gynaecomastia >
Hallerman – Streiff
Happy Puppet **
Hemi – megalencephaly
Hemiplegia **
Herpes pemphigoid >
Hollister – Levy
Holoprosencephaly ** (USA)
Horner
Holt – Oram
Hypercalcaemia
Infantile **
Hyperekplexia
Hypocalcaemic hypocaluria
Hypogamma
globulinaemia **
Hypomelanosis of Ito **
Idaho
Joubert **
Klippel – Feil **
Klippel – Trenaunay – Weber **
Knee, congenital dislocated
Kugelberg – Welander **
Lacrimo – auruculo – dento – digital
L.A.D.D.
Lamellar exfoliation

Landau >
Landau – Kleffner **
Laurence – Moon – Biedl **
Lennox – Gasteaut **
Lichen sclerosis atrophicus
Linear sebaceous naevus
Lissencephaly **
Lowe **
Lymphoedema of arm > (adult)
Macrodystrophia lipomatosis
Majewski >
Marfan **
Maxillonasal dysplasia
McCune Albright
Melnick – Needles
Moebius **
Motor & sensory neuropathy,
hereditary **
Muscular dystrophy,
congenital **
Mulvihill – Smith >
Myelinisation, delayed
Myotonic dystrophy **
Nager
Neimann – Pick **
Nesidioblastosis **
Neurofibromatosis **
Neutropenia **
Noonan **
Nystagmus **
Occipital encephalocele
Ocular – cerebral – facial
Oculo – dento – digital
Ondine's **
Oro – acral
Osteopetrosis **
Ohtahara **
Pachygyria
Pallister – Hall >
Pancreatitis **
Pars plantis >
Patau (Trisomy 13) **
Pelizaeus – Merzbacher **
Peroneal muscular atrophy
Peutz – Jegher
Plott >
Polyostotic fibrous
dysplasia
Prader – Willi **
Premature sexual maturation **
Proteus
Rett **
Rubinstein – Taybi **
Russell – Silver **
Sacral agenesis **
Schizencephaly
Scoliosis **
Scotopic sensitivity
Segawa's dystonia
Sensory & motor neuropathy,
hereditary
Sensory integration disorder
Septo – optic dysplasia **
Silver Russell **
Smith – Magenis **
Sotos **
Spinal muscular atrophy **
Stickler **
'Stiff baby'
Sturge – Weber **
Supra – Bulbar palsy **
Tactile sensitivity
T.A.R. **
Testicular feminisation
Tolorosa – Hunt > (adult)
Thromboasthenia, Glanzmann **
Treacher – Collins **
Trichorhinophalangeal, type 1 >
Tuberous sclerosis **
Turner **
VATER Association **
Weaver **
Werdnig – Hoffman **
West **
Williams **
Wiskott – Aldrich **
Wolf (deletion 4p, 4p –)

PUBLICATIONS FROM IN TOUCH

Coming to Terms with Mental Handicap - Ann Worthington
Reprinted 1985

This book provides parents of newly diagnosed children with an opportunity to share the experiences, described in their own words, of other parents who have come through those early years. It also contains information of a practical nature to enable parents to face the future with greater confidence.
Price 9.50

Useful Addresses for Parents with a Handicapped Child - Ann Worthington. Sixth Edition 1991

Addresses of organisations and support groups, toys and play, aids and equipment, education, further education, long and short term care, holidays, finance and rights, publications.
106 pages Price 4.75

Glossary of Mental Handicap and Allied Physical Disorders - Ann Worthington. New Edition available shortly

This book provides a brief description of some of the conditions which result in mental handicap in association with recognisable physical features. It also provides an explanation of the terminology used in medical literature to describe the features of such disorders. Price 7.50

All available from: IN TOUCH TRUST (Price includes p & p)
10 Norman Road
Sale
Cheshire M33 3DF

ORDER FOR IN TOUCH PUBLICATIONS

Please send me the following :- (All prices include post and packing)

_ _ _ copy/ies 'Useful Addresses for Parents with a Handicapped Child.' 6th edition
Price £4.75.

_ _ _ _ copy/ies 'Glossary of Mental Handicap and Associated Physical Disorders'.
Price £5.50.

_ _ _ _ copy/ies 'Coming to Terms with Mental Handicap'
Price £7.50.

Name & address _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _

_ _

I enclose a cheque/postal order (payable to In Touch) for _ _ _ _ _

I would like an invoice/remittance advice before making payment [ ]

Please return this slip to In Touch Trust, 10 Norman Road, Sale, Cheshire. M33 3DF

UNDERSTANDING NOT LABELLING

RARE SYNDROMES AND CONDITIONS GIVING CAUSE TO LEARNING DISABILITY

The overall theme of this issue of the PMLD Link Bulletin is "rare syndromes". Increasingly researchers are identifying the genetic and other causes of rare syndromes and information on the management, care, and treatment, of people with such syndromes and conditions is being disseminated in language understandable to those outside the medical profession. It is therefore timely that PMLD Link should draw attention to the need for all of us working in the field of learning disabilities to be aware of these breakthroughs, as well as using all available information to help us provide quality services that truly meet the needs of all those for whom we care.

There is at present an opinion amongst a minority of professionals that we do not need to put a name to a syndrome or condition. They feel that this in some way labels the person with disabilities, that it is not necessary in order to provide quality services. There is also a fear that we could end up with further segregated services, services geared towards specific syndromes or groups of conditions or diseases. This is a very naive view. There are a number of very practical and valid reasons why it is vitally important to know and understand the causation underlying the profound and multiple disabilities of the people with whom we work, and the consequences that ensue. We also need to be aware of the many organisations that exist where we can seek further specific information and help. In this short article I will try to address these two issues.

WHO NEEDS TO KNOW AND WHY

The person with disabilities:
All of us working with people with disabilities owe a duty to them to know and understand as much as possible about their particular syndrome or condition. They have a right as citizens to be respected, understood and to receive services that meet their needs. We can only do this effectively if we are informed about their requirements. Learning as much as possible about their respective conditions is one way of achieving this aim.

The parents:
Parents desire for information must be met. They have a right to be fully informed on the specific syndrome or condition of their child. Barry Carpenter, in his editorial in the last issue of PMLD Link, articulated the feelings of parents very clearly. After the initial shock, the devastating news that their child has learning disabilities has sunk in, parents do want to know the cause of their child's condition. They want a name, an explanation, and information on how the child will progress. If we have another child will she/he be affected ? What about other members of the family ? Is the condition hereditary ? Should we have genetic counselling ? Is there an organisation or support group we can join ? These are just some of the questions to which parents want answers. If the child has an

identified syndrome or condition then at least some answers can be provided.

The Family:
The family, the siblings, and wider family members - uncles, aunts, grandparents, cousins - all these family members want as much information as possible. Their questions are similar to those of parents. It is important for all family members to be able to talk about the person with disabilities in a positive way. They want to be knowledgeable about the condition or syndrome in order to dispel the fears and ignorance of friends, neighbours and the wider community. They also need to know the prognosis. This will help them and the parents cope through times of stress, regression and so on. If their relative has a genetic disorder the family have a right to professional genetic counselling.

The service providers:
All service providers, those working in education, health, social, and residential services should have access to sources of information on rare syndromes, conditions and diseases. I am not suggesting that we all become experts on every syndrome we encounter. However, it is imperative to understand, for example, if a girl with Rett Syndrome loses some of the skills previously acquired, that this is due to the fact that this condition is progressive and the girl is in a regressive stage, not that the teacher or service provider is somehow employing incorrect intervention strategies. Similarly, it is important to understand that difficult, stereotypic or self-injurious behaviours, are associated with some specific syndromes, for example, Lesch-Nyhan or La Tourette Syndrome and that strict hygiene practices must be employed when caring for a child with Cytomegalovirus. Our teaching approaches and intervention strategies may need to be altered to take account of the specific features of different conditions or syndromes.

SOURCES OF HELP AND INFORMATION

Although there is a considerable amount of research being undertaken into conditions related to learning disabilities, the outcomes of this research is not always readily disseminated to hands-on service providers. So, where can we obtain this information, what resources are available to service providers? There are a number of publications available that give basic information on specific conditions and rare syndromes that can be used as a first reference source. Details of relevant publications are given below.

Publications:

The following are just a sample of the many resource directories and guides that are now available.

CaF, (1991) <u>CaF Directory of Specific Conditions & Rare Syndromes</u>, London, Contact a Family. CaF's directory lists in alphabetical order conditions and rare disorders for which there are support networks. The entries contain brief medical

descriptions of the condition, gives details of inheritance patterns and pre-natal diagnosis. Information on related support networks, their publications and services are also given. The directory is produced in an A5 loose-leaf ring binder format to allow regular up-dating. This publication is easy to use, very informative and a requirement in all establishments providing a service to people with profound disabilities and their families.

Worthington, A. (1993) Glossary of Syndromes Associated with Learning Difficulty, Cheshire, In Touch. This book is a lay person's guide to understanding the complex medical terminology associated with specific conditions and syndromes identified with learning disability. It is invaluable when trying to decipher a mispronounced or misspelt word or term. As well as giving definitions of the medical terms the 'Glossary' also contains brief details of specific syndromes and conditions. It is a very good reference source. The book is published by In Touch and is available from the address below.

Thomas, S. (1986) Genetic Risk: A book for parents and potential parents, Penguin, London. As its title implies this book is specifically written for parents. However, it is equally valuable to non medical professionals. The language used is easily understood and medical terms used are explained clearly. Regrettably, this book is currently out of print but you may be able to obtain a copy in specialist book shops or failing that from your local library.

The above three publications are all relatively inexpensive and are suitable for use by both parents and professionals.

The following publications are much more medically orientated, are relatively costly to purchase but are excellent resource reference books.

Jones, K. L. (ed) (1988) Smith's Recognizable Patterns of Human Malformation: 4th Edition, W. B. Saunders Company, London. The language used is heavily medical and terminology inconsistent with UK usage. However, this is an invaluable source and is the acknowledged reference book on this topic. All recognised syndromes and conditions are listed. The introduction to the book says "The major text is devoted to patterns of malformation, as contrasted with patterns of deformation due to mechanical factors (this is the subject of a separate text - see below). There are also chapters on normal and abnormal morphogenesis, genetics and genetic counselling, psychologic adaption to the child with structural abnormalities, minor anomalies and their relevance, a clinical approach toward a specific diagnosis for certain categorical problems and normal standard of measurement for a variety of features". This is an invaluable reference book.

Graham, J. M. (ed) 1988) Smith's Recognizable Patterns of Human Deformation, W. B. Saunders Company, London. Companion book to the above. This book deals with anomalies that represent the the normal response of a tissue to unusual mechanical forces that are termed deformations, in contrast to malformations - see above.

These two books, together with a good medical dictionary such as **Dorland's Illustrated Medical Dictionary (1988)**, and the non-medical references given above, would form the basis of a very good reference library for any school or adult service.

Organisations -Umbrella Groups:

There are in existence a great number of voluntary organisations and self-help groups related to specific syndromes. There are also umbrella organisations that cover groups of conditions. The remit of the various organisations vary tremendously. Some are relatively small depending on the rarity of the syndrome or condition they represent. Others act as a contact source for families. Many are quite large voluntary organisations that sponsor research, organise conferences and seminars and publish books and pamphlets. All provide information on the respective conditions they represent. Some produce videotapes, and most publish a newsletter or journal, available by subscription. The individual organisations are too numerous to list here, however, a brief description of the larger groups and also the main umbrella organisations is given below and their addresses are listed at the end of this article.

Contact a Family (CaF): CaF is a national registered charity concerned with families who are caring for a child with any type of disability or special need. They provide services at national, regional and local level. Services include: Advice and support to parents throughout the UK: A Contact Line, through which parent advisers answer telephone or written enquiries from other parents and also professionals; Advice and support to national parents' groups concerned with rare syndromes and specific conditions: Quarterly journal - 'Share an Idea'; Fact Sheets on a variety of topics related to disability. CaF publishes a directory on specific conditions and rare syndromes for which there is a support network (see above). In addition, CaF, holds a data base on a substantial number of conditions and syndromes in addition to those listed in their directory.

Genetic Interest Group (GIG): The Genetic Interest Group, a registered charity, is an umbrella group for voluntary organisations concerned with genetic disorder.
Their aims are:
To discuss matters of mutual concern both within the group and with outside agencies.
To represent the consumers' and families' interests with these outside agencies.
To promote medical and public awareness of genetic disorders.
To monitor the effect of current statutory provision and promote the development of genetic services.
The Genetic Interest Group will respond to enquiries from parents and professionals.

In Touch - Contacts and Information Service for Parents of Children with Special Needs: In Touch, is a registered charity. Although primarily a service for parents, is also used extensively by professionals working in the field of disability. As its name implies, In Touch directs enquirers to sources of

advice on all aspects of disability. In Touch has a comprehensive library on rare disorders and will provide information to professionals and parents. They also put families in touch with support groups for specific syndromes and conditions, and with other families dealing with the same disability who have expressed willingness to be contacted by other parents. In Touch publishes a quarterly newsletter, which, as well as giving up-dated information on contact and support groups, publicises requests from parents and professionals for contacts related to specific syndromes, and also gives details of new publications, conferences and seminars etc. Additionally, In Touch, publishes books and pamphlets on disability matters, including the 'Glossary of Syndromes'; and 'Useful Addresses for parents with a Handicapped Child' (Worthington 1991 & 1993).

Research Trust for Metabolic Diseases in Children (RTMDC): The RTMDC is a registered charity, representing as an umbrella organisation, all the metabolic disorders which are not supported by other major organisations. It offers: Medical information to parents and professionals; Support for families, through counselling and advice; Support and counselling on bereavement; and some financial support. Organises: An annual national conference; Development of local groups; The establishment of parent support networks; Meetings for specific conditions; Publishes: Newsletter three times per year; Question and Answer leaflet; other leaflets and pamphlets.

Society for the Study of Behavioural Phenotypes (SSBP): The main focus of this organisation is the study of specific behavoural phenotypes associated with biologically determined disorders that lead to mental handicap/learning disability, for example Fragile X and Rett Syndrome. They organise conferences and seminars on the topic of behavioural phenotypes and disseminate research findings.

Organisations - National:

In addition to the umbrella organisations there are a number of organisations related to a specific syndrome or condition. For example, Rett Syndrome Association; Tuberous Sclerosis Association; Prader-Willi Syndrome Association; Fragile X Society Down's Syndrome Association etc. Additionally, the large national voluntary organisations, such as Mencap, Spastics Society, Royal National Institute for the Blind (RNIB), SENSE, Enable (Scottish Society for the Mentally Handicapped), Scottish Council for Spastics etc, will have details of the organisations related to specific and rare syndromes and conditions. Some of these organisations, such as Mencap and RNIB have a department that is concerned with profound and multiple disability.

Research:

Research into the causation factors of learning disability is ongoing. To find out what is currently known or being investigated in relation to a specific condition or syndrome it is best first to contact the support group or organisation related to the respective conditions. Research workers publish findings in the academic press and also through journals such as

The British Institute of Learning Disability's (BILD) **Mental Handicap Research** or their **Current Awareness Service (CAS)**, both available on subscription from BILD and **The Journal of Intellectual Disability Research**, available via Mencap.
Details of applied research related to learning disability and/or profound and multiple disability can be obtained from university departments involved in research in this field, for example, **the Hester Adrian Research Centre**, University of Manchester and **The White Top Research Unit**, University of Dundee.

As stated at the outset, the aim of this article is not to encourage further labelling of people with learning disabilities or to imply that we need to develop segregated services for people with specific conditions. Its purpose is to ensure that we all recognise the importance of learning as much as possible about the specific syndromes and conditions of the people for whom we provide a service, in order that our services meet their needs. The addresses for all organisations mentioned in this article are given below.

Loretto Lambe June 1993
White Top Research Unit
University of Dundee

REFERENCES:

CaF, (1991) CaF Directory of Specific Conditions & Rare Syndromes, London, Contact a Family.

Dorland, I. (1988) Dorland's Illustrated Medical Dictionary, W. B. Saunders Company, London.

Worthington, A. (1993) Glossary of Syndromes Associated with Learning Difficulty, In Touch, Cheshire.

Worthington, A. (1991) Useful Addresses for Parents with a Handicapped Child, In Touch, Cheshire.

Thomas, S. (1986) Genetic Risk: A book for parents and potential parents, Penguin, London.

Jones, K. L. (ed) (1988) Smith's Recognizable Patterns of Human Malformation: 4th Edition, W. B. Saunders Company, London.

Graham, J. M. (ed) 1988) Smith's Recognizable Patterns of Human Deformation, W. B. Saunders Company, London.

ADDRESSES:

British Institue of Learning Disability (BILD)
Wolverhampton road
Kidderminster
WORCS DY10 3PP
Tel: (0562) 850 251

ENABLE
13 Elmbank Street
GLASGOW GG2 4QA
Tel: (041) 204 4398

Genetic Interest Group
c/o Institute of Molecular Medicine
John Radcliffe Hospital
OXFORD OX3 9DU
Tel: (0865) 744 002

In Touch
10 Norman Road
Sale
CHESHIRE M33 3DF
Tel: (061) 905 2440

Prader-Willi Syndrome Association (UK)
30 Follett Drive
Abbots Langley
HEREFORDSHIRE WD5 OLP
Tel: (0923) 674 543

Rett Syndrome Association (UK)
Hartspool
Golden Valley
Castlemorton, Nr Malvern
WORCESTERSHIRE WR13 6AA
Tel: (068) 481 357

SENSE
(National Deaf-Blind & Rubella Association)
11-13 Clifton Terrace
LONDON N4
Tel: (071) 278 1005

Contact a Family
16 Strutton Ground
LONDON
SW1P 2HE
Tel: (071) 222 2695

Fragile X Society
53 Winchelsea Lane
Hastings
EAST SUSSEX TN35 4LG
Tel: (0424) 813 147

Hester Adrian Research Centre (HARC)
University of Manchester
Oxford Road
MANCHESTER M13 9PL
Tel: (061) 275 3333

Mencap PIMD Section
Piper Hill School
200 Yew Tree Lane
Northenden
MANCHESTER M23 OFF
Tel: (061) 889 4161

Research Trust for Metabolic Diseases in Children (RTMDC)
Golden Gates Lodge
Weston Road
CREWE CW1 1XN
Tel: (0270) 250 244

RNIB
Service on Multiple Disability
224 Great Portland Street
LONDON WIN 6AA
Tel: (071) 338 1266

Scottish Council for Spastics
22 Corstorphine Road
EDINBURGH EH12 6HP
Tel: (031) 337 9876

Society for Behavioural Phenotypes (SSBP)
The Park Hospital
for Children
Old Road, Headington
OXFORD OX3 7LQ
Tel: (0865) 226 321

The Spastics Society
12 Park Crescent
LONDON WIN 4EQ
Tel: (071) 636 5020

Tuberous Sclerosis Association (TSA)
Little Barnsley Farm
Catshill
Bromsgrove
WORCS B61 ONG
Tel: (0527) 71898

White Top Research Unit
Department of Social Work
University of Dundee
DUNDEE DD1 4HN
Tel: (0382) 29598

LESCH-NYHAN SYNDROME

Lesch-Nyhan syndrome results from an inborn error in the metabolism of purines, which leads to an almost complete absence of the enzyme HPRT (hypoxanthine-guanine-phosphoribosyl-transferase). The syndrome is a X-linked recessive trait, the abnormal gene being responsible for the absence of HPRT activity. While until recently, therefore, Lesch-Nyhan was viewed as affecting males only, a recent claim has been made of the discovery of the condition in a female. Lesch-Nyhan syndrome is associated with progressive neurological deterioration throughout life, with death occuring in the second or third decade.

The consequences of the metabolic disorder are extensive. Hyperuricemia, hyperuricosuria, choreathetosis, spasticity, learning disability, and self-mutilation have all been identified as part of the syndrome. To readers of this journal, it is perhaps the last two aspects of this list that are of particular significance.

Lesch-Nyhan syndrome is associated with a range of intellectual ability. While some individuals will be on the borderline of profound learning disability, most will be intellectually more able. Several reports emphasise that the combination of cerebral palsy and self-mutilation leads to an underestimation of intellectual ability, and undoubtedly some boys (or young men) with the syndrome have average intelligence. There is remarkably little reference in the literature to their communicative abilities, except with reference to what they say about their own predisposition to mutilate themselves.

This tendency begins between the first and third years of life, and is directed primarily to the person's lips, fingers, inside of the mouth and lips. This behaviour can lead to permanent tissue loss. A range of other difficult behaviours have been noted including skin-picking and aggression to others. As yet the link between the neurological functioning of the person with Lesch-Nyhan syndrome and self-mutilation has not been established, though several hypothesis have been advanced. A variety of unsuccessful psychopharmacological interventions have been reported. It has been suggested that until dopamine neural transplants become clinically applicable, gene replacement therapy available, or effective drugs found, we will have to depend on behavioural methods and/or restraint to reduce self-mutilation in those with Lesch-Nyhan syndrome. There are a number of published behavioural studies showing some degree of effective suppression. Controversially, extraction of the teeth is proposed in some texts, though even in the dental literature this has been opposed as too drastic and permanent. A more conservative approach involves the use of mechanical restraints. It is interesting to note that there are several reports of individuals with Lesch-Nyhan syndrome pleading with their carers to be kept in, or put in, restraints.

There is no single, comprehensive account of the management of Lesch-Nyhan syndrome. Various papers report on the successful management of hyperuricemia and unsuccessful attempts to counteract the disordered purine metabolism and hence mitigate the ensuing neurological deterioration. Specific approaches to dealing with spasticity and coreoathetosis and orthopaedic problems have been reported.

Families are confronted with an inevitable conflict between immobilising the person and granting freedom of movement. However, there is little reference to families or family functioning with respect to this condition. Similarly, to the best of our knowledge, there are no comprehensive educational strategies for encouraging development in people with Lesch-Nyhan syndrome.

Lesch-Nyhan syndrome remains one of the most distressing and challenging conditions. Research is patchy, but there are indications in the literature that progress is being made on several fronts to ameliorate the condition if not to cure it. I have recently prepared a review of the literature on Lesch-Nyhan syndrome which will shortly be available. This is preparatory to developing research on the syndrome. I would therefore welcome hearing from carers and professionals who are in contact with boys and young men with this condition. In particular it would be helpful to hear about any aspects of educational and behavioural work that is being undertaken. Please write to: **PROFESSOR JAMES HOGG, DIRECTOR, WHITE TOP RESEARCH UNIT, THE UNIVERSITY, DUNDEE DD1 4HN.**

STAFFORDSHIRE COUNTY COUNCIL

Quince Tree School

Headteacher
Mrs. V. A. Vernon
Cert Ed. A.C.P. Dip.Sp.Ed. L.C.P.

QUINCE,
TAMWORTH
B77 4EN

Telephone: Tamworth 56719

Quince Tree is an SLD school in Tamworth. In January we participated in an LEA review and we were asked to take part in a pilot, the quality of learning, quality of teaching, assessment, recording and reporting would follow the OFSTED criteria by inspectors who had recently undergone their training.

The staff welcomed the opportunity to participate and the procedure was informative and the feedback excellent, commending staff on how we had given our pupils access to National Curriculum, on the management structure, on the caring environment and on the high achievements and behaviour of the pupils.

But there was one element of the review that caused us great concern. All staff were observed teaching on two occasions, each time for 45 minutes. Following the observation staff were given feedback and as we were piloting they were informed of their score. 90% were scored from 3 to 1 (1 being excellent). On observing the PMLD group we were informed that they would not be included, when asked why we were told 'there was no evidence of learning in the 45 minutes so the teacher would have scored 6 - even though the lesson was wonderful!

In this particular group of pupils many have regressive conditions and, in fact, one pupil died two weeks after the review. As OFSTED stands there is little flexibility to differentiate their criteria to these pupils.

On writing to OFSTED expressing our concerns they replied telling us that 'the inspectors can assess standards in learning including the pupils' ability to sustain concentration' - many of the pupils in this group can't even give eye contact.

Once again we are the forgotten few, National Curriculum was not written with us in mind neither has OFSTED.

We looked at the review positively, we welcomed the challenge to make improvements, we want to offer a quality service that is second to none, OFSTED will only help us to achieve that if it is relevant to our pupils.

V.A. Vernon,
Headteacher.

CREATIVITY WITH PEOPLE WITH LEARNING DISABILITIES.

-themes using art, craft, music and drama.

Orchard Hill Further Education Centre provides educational courses for adult students with profound and severe learning disabilities. The Centre is situated at Orchard Hill- a long-stay Community Health Care Services provision, and is funded jointly by Sutton Education Authority and by Community Health Care Services.
The Centre offers a wide range of courses to students living on site and in the community.

Working with adults who have a range of strengths and needs requires flexible and creative teaching approaches:-

Making Equipment With Students For Students.

Making equipment for use in teaching sessions and theme-based activities is time-consuming for staff. However, student involvement in equipment making can become a valuable learning opportunity in its own right.
Students who enjoy participating in making/doing are encouraged to participate in making props for a theme e.g. Making a stream out of blue tissue paper, with cardboard boulders, painted with finger-paints and covered with cellophane for the Scottish Theme (see below).
With students who are resistant to using equipment, the focus is on providing associated sensory experiences e.g. Making musical instruments and concentrating on the sounds produced by the lentils as they are dropped into the container, the visual stimulation of the shiny paper used to cover the instrument, and the tactile stimulation of the sticky Sellotape.

Using Equipment Creatively.

Ideally home-made equipment is used by the students who made it, but can also be used by others. It is important to be aware of individual student needs and to adapt the use of the equipment accordingly. Be inventive!
For example, if a student is physically unable to hold a musical instrument independently, it can be used by the member of staff to tap out rhythms on different body parts as part of a body awareness activity.
Students can be involved in setting up and tidying away equipment during sessions. This is valuable for reinforcing concepts of object permanence, marking the beginning and end of activity, encouraging participation in household skills and enabling students to communicate choice of activity by locating the equipment.

Steps For People Who Seem Difficult To Engage In Activities.

Why does my student push everything away?
Is it me? Is it because it's new? Is it the way it's being presented? Are there other distractions? Am I allowing him/her enough time to respond? Is it intrinsically rewarding?.....
Or is it a genuine dislike?
These are some of the thought processes we have to go through in order to assess students' likes and dislikes. This information forms the foundation for the creative approaches required to engage the student.
The aim is for the student to become progressively more involved in the activity over a period of time:-

Tolerates
|
Some interest
|
Increased interest/
Familiarity
|
Minimal participation
|
Increased participation
|
Initiation

It's important to congratulate students on their successes. A little encouragement goes a long way!

Being Creative Without Equipment.

Equipment is not essential!

Human interaction is an endless source of stimulation - cheap, adaptable, non-technical and challenging.
A few spare minutes of close interaction can be highly valuable. Staff observe closely the movements, gestures and vocalizations of the students and respond by copying or 'answering' the signals. Initiation and control are shared and students are encouraged to lead the interactions.

Holding It Together In A Theme.

A theme provides a framework for activities and is motivating for both students and staff. The approaches described above can be incorporated into a theme; for example, students can make their own equipment or 'props' for the theme and both home-made and bought equipment can be used creatively - a footspa can become a bubbling stream in the Scottish Theme.

The accompanying themes have proved successful.

Caroline Allen and Helen Mackay
Orchard Hill FE Centre
6 Elm Avenue
Queen Mary's Hospital
Carshalton Beeches
Surrey. (081-770 8319)
VISITORS WELCOME!

Using the principles of Conductive Education with children with p.m.l.d.

Just over three years ago Conductive Education (C.E) was introduced as the teaching method for the entire school day,in SPEND (Special Physical Educational Needs Department) for children with PMLD. Of the eighteen children only two are semi-ambulant and three are able to communicate with symbols or signs,all have their own sounds to communicate their feelings.
I became interested in this approach when a session was introduced by the physiotherapist once a week. I attended a course at Castle Priory on The Basic Motor Pattern. This was followed later by a similar course held at the same place. I was supported by the physiotherapist after my course. C.E. equipment, ladderback chairs,plinths and special potty chairs were bought, and hip spicas were made for individual children.
The equipment is as essential as the approach as the children sit round a table to work and eat like their peers. They also go to the toilet like their peers. Sitting round the table became the key feature of the approach. Staff based in SPEND and visitors alike saw each child as an individual with special needs rather than a child with certain problems. Each child has their own aims each term and objectives each session to achieve to help them become "functional". That is, to become as independent as they can and to be aware of the immediate environment realising they have control over it,through sounds and actions.
The advantages of C.E. are numerous and the achievements by the children quite apparent to parents and professionals alike. There are five principles of C.E;the conductor or the adult who leads the session. She can use pre-written programmes so does not need to be the teacher. The remaining four principles are the most important as they are the factors the children respond to. The work is always carried out in groups,there is a highly structured routine at all times,the same language and "props" are used all day,there is always rhythmical intention. There is also a positive reward system of many songs and individual attention throughout the programmes. I have found it is the routine and language that the children respond to. The children respond to the language outside the classroom in different learning environments including pony riding, cookery and music lessons, taken by visiting musicians.
I am very keen to hear from other teachers and professionals who use C.E. principles with children of all ages especially the pre-school and older teenager. I have the opportunity of some study days and would like to visit like - minded professionals.

Judith Pilkington.

I can be contacted at The Robert Clive School
Hearne way
Monkmoor
Shrewsbury
Shropshire.

Tel :0743 351091.

The National Council for Educational Technology (NCET) has recently published two short illustrated information sheets: "An introduction to the use of multi- sensory environments" and "I.T. for adults with learning difficulties". These will interest readers of PMLD LINK who want basic guidance on how Information Technology (in its widest sense) can meet a variety of needs in the developing child or adult with severe or profound learning difficulties. Both papers have examples drawn from real life, lists of equipment and resource materials, and advice on sensible policy and purchasing decisions in a confusing world.

"Multi- sensory environments" draws together the experience of practitioners in the SLD/PMLD field and looks at how multi-sensory experiences can establish and improve perceptual and cognitive skills. The paper raises an awareness of the merits of different philosophies – for example how the Snoezelen 'client-led' approach contrasts with the sensory objective training method.

This is fundamentally a practical information sheet with ideas on who to ask for help and how to ask the right questions. It also confirms that there is no absolute necessity to spend enormous amounts of money on setting up a multi sensory room and that low-cost solutions can be effective. The final section *First steps in setting up a sensory environment* identifies seven essential questions which will help to avoid making mistakes - expensive or otherwise.

"I.T. for adults with learning difficulties" proposes that computers can provide many useful activities and learning opportunities. Some of these applications are introduced in a well-illustrated paper which does not set out to be a definitive software list (though there are many useful examples) but rather to help tutors and carers choose appropriate strategies. It is divided into six basic areas of development – *Communication, Developing Literacy, Life Skills, Art and Design, Information Handling,* and *Leisure,* each with suggested resource software for a range of popular computers. These are sandwiched between the remaining two sections, *Initial Activities* which helps both the learner and the supporter to make a start with computers, and *Authoring Packages* showing how, with just a few I.T. skills, materials can be made to match closely the individual learner's needs.

Readers who are interested may request their free copies of either publication, and details of other appropriate NCET materials by contacting:

Terry Waller
Senior Information Officer - Special Needs
National Council for Educational Technology
Sir William Lyons Road
Science Park
University of Warwick
Coventry
CV4 7EZ
Tel. No.: 0203 416994

YOU'RE A REHABILITATION ENGINEER ?

SO WHAT DO YOU DO ?

• *If I had a penny ....*

I do not help ex-cons fix cars! When Carol first asked me (quite some time ago!) to write a short article for PMLD LINK about what I do, I thought that she was just desperate for articles. I have of course come to realise that there are very few rehabilitation engineers working with people with PMLD and so very few people know much about us. Unfortunately we are a bit like a pack of cards; there can't be many more than 50 of us and no two are alike. Because of this I will now attempt to give a beginner's guide to rehabilitation engineering in general, without using any technical terms or words I can't spell. I will also write a little bit about myself because I was asked to.. and.. well.. all men enjoy talking about themselves anyway.

• *A rose by any other name ...*

Of course anybody who owns a screw driver can call themselves an engineer and the word rehabilitation is pretty ambiguous, so it's no wonder nobody knows whom we are. It wouldn't help if I told you that some of us call ourselves bioengineers, clinical engineers or medical physicists, depending on the organisation we work for. The name on my own door says Clinical Rehabilitation Officer (it wasn't me that put it there). In the end it's not really important what we are called. In order to be the real McCoy you have to have two things ; some real engineering qualifications and a lot of experience and knowledge of the group you're working with. Having only one of these can waste a lot of time and money.

• *Big Brother ..*

Bioengineering is our big brother subject with many special interest groups such as biomaterials, medical informatics, blood flow and physiological

measurments. We like to get together every now and then to share ideas, moan about common problems and to give ourselves professional credibility.

Rehabilitation Engineering is a relatively small subject dealing with the 'hands on' use of technology by people with disabilities. It has recently been defined by the Biological Engineering Society (UK) in a rather boring but informative manner as : "... *the clinical application of engineering principles and technology to restore or improve as far as practicable the physical, mental and social function and well-being of a disabled person. It is an important element of a comprehensive rehabilitation service..... and includes (a variety) of activities, services and subjects of research, design, development, production and marketing...:"*

Their list of activities includes :-

- Communication systems for people with speech and language impairment;
- Assistive devices for all activities of daily living in domestic, educational, vocational, recreational, social and institutional environments;
- Environmental control; *(That's controls for doors, lights, t.v., phones etc)*
- Wheelchairs and special vehicles, including their controls;
- Specialised prosthetics; *(artificial limbs)*
- Specialised orthotics; *(supports for limbs that don't work)*
- Special Seating;
- Functional electrical stimulation;*(electronics to control paralysed muscles)*
- Gait analysis;

Obviously rehabilitation engineers are not isolated but work in interdisciplinary teams with a wide range of other professionals.

The organisation which I work for, Tayside Rehabilitation Engineering Services (TRES), is at least active in all of these areas, but only a few regions have the integrated, comprehensive service available in Tayside. My particular role within TRES is in the areas of communication aids, specialised powered wheelchairs, environmental controls and aids for early development. I provide technical support for assessments, purchasing, design, manufacture/modification, maintenance, etc.

Since joining TRES and providing this broad range of services I have naturally met people with a wide range of problems. It soon became obvious that the most difficult yet rewarding work was with those with multiple disabilities. Those with PMLD, by the very nature of their impairments, represent a comprehensive challenge to a wide range of service providers, including reha-

bilitation engineers. The constraints placed upon the services I provided made it very difficult, if not impossible, to provide the level of services I felt were required. It is questionable whether this group has ever benefited from the use of technological aids that have for many years enabled more able people to overcome some aspect of their disability.

• *Opportunity knocks ...*

When the opportunity arose to work part time with the White Top Centre and Research Unit (a new initiative in Dundee for adults with PMLD), naturally, I welcomed it with open arms. In the short period that I have spent in this area I have been encouraged by how much technology is already being used, not just switches and computers but think also of the adapted toys, Meldreth Games, SoundBeam, Snoezelen, ... It has not surprised me however to see many opportunities being missed due to a lack of resources and expertise. In particular I feel that many of the techniques already developed for mobility, communication and self help skills are relevant to this group, albeit that they are more complicated and costly to apply.

• *Is there anybody out there ...*

If you happen to be an engineer and are reading this, then perhaps you could get in touch. Indeed I would be interested in hearing from anybody working with technology in this field. Perhaps we could start a technology page in PMLD LINK informing everyone on latest ideas, products or research.

John Colvin
White Top Research Unit
Dept. of Social Work
University of Dundee
DD1 4HN Tel : 0382 28589

Vibro-MediCo

I feel rather excited about a new product, perhaps more accurately, half new. It is the vibro Base Unit, now well known amongst teachers and physios for its unique type of vibration, to which I have now added sound. At least the prototype is about to come off the drawing board and the feedback so far is very good.

Appoximate price: Vibro base unit with speaker – £615-670 (depending on size)

1/ Cycloidal vibration for the relaxation of spasticity together with all the benefits that provides.

2/ The teaching and development of motor skills by means of reward, reinforcement, and cause and effect.

3/ Now sound, fully controlled, with or without vibration, via speakers fitted under the unit. Controlled by cassette player linked to the Vibropulse Controller for the provision of music or other recorded material.

This should be exciting news to all associated with PMLD children, and adults for that matter. I have been asked many times over the years to provide just this, and now, by the time schools return from their Summer holidays, it should be ready and waiting.

VIBRO – MEDICO 20 Church Road, Hadleigh, Essex SS7 2DQ Telephone: 0702-557966

Clifford S.O. Black F.Inst. S.M.M.

Royal National Institute for the Blind

RNIB

Helping blind people to see a future

224 Great Portland Street
London W1N 6AA
Telephone 071-388 1266

FOCUS FACTSHEET

"LOOKING FOR EYE PROBLEMS

IN PEOPLE WITH LEARNING DIFFICULTIES"

We found it necessary to produce this factsheet because we found that very few people with severe learning diffiuclties, or who function as if profoundly disabled have had their sight tested.

As the incidence of visual impairment is higher in people with learning difficlties, it is particularly sad that this knowledge has not been used to develop comprehensive screening programmes across the country. Unfortunately many staff and carers simply do not know what to look for. It is not uncommon to discover that people have gone through life unnecessarily handicapped – especially the people who simply need glasses, but at the present time give the impression of being severely visually impaired.

The leaflet is available free of charge from Julia Wensley or myself at this office.

Gill Levy
Information and Practice Development Officer
Multiple Disability

Book Review

"Peter's New Home" and "A New Home in the Community".

- Sheila Hollins and Deborah Hutchinson.

"Jenny Speaks Out" and "Bob Tells All".

- Sheila Hollins and Valerie Sinason
  Illustrated by Beth Webb
  Sovereign Series: St George's Mental Health Library
  Cost: £7.50 each.

These two pairs of books deal with sensitive and pertinent issues for people with learning disabilities. Written in an easy to read style that could be accessed by adult learners with learning disabilities, these books describe some of the transition to adulthood challenges that may present themselves.

"Peter's New Home" is designed to help raise the difficult issue of leaving home which "can be rather a frightening experience". Similarly "A New Home In The Community" is designed to help people with learning disabilities make a happy transition to a new home.

In clear pictures and succinct text the books depict, respectively, the moves of Peter and Simon, to a group accommodation setting. The books are positive in their outlook, whilst acting as an excellent basis for discussion and exploration of personal feelings.

People with learning disabilities may have been the victims of sexual abuse. To describe their trauma, particularly with limited communication skills, may be a complex process. "Jenny Speaks Out" and "Bob Tells All" are designed to help people with learning disabilities who have experienced sexual abuse, to confide in a trusted confidant. The bold pictures and honest text used in these two books should help engender a frank forum for discussion of issues of sexuality and sexual abuse.

In all four books the illustrations are particularly striking. The use of colour to convey emotion is very effective. For example, Peter's trauma as he tries to cope with the fear and frustration of sexual abuse is portrayed in purple and blue. The illustrations are graphic, but necessary to communicate a sensitive subject, for too long taboo in relation to people with learning disabilities.

I highly commend these books, part of a developing series from St George's Mental Health Library, to people with learning disabilities, and all who are concerned with their welfare.

Barry Carpenter
Senior Lecturer
Westminster College
Oxford

Academic Year 1993/94

P M L D - Link

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