

PMMLD LINK

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

Spring 2010

**International
Perspectives**

PMMLD Link

Vol 22 No. 1 Issue 65

Registered Charity No. 1121085

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

International Perspectives

Guest Editorial: International Issues	Penny Lacey	1
The development of an Integrated Care Pathway for services to children with complex physical healthcare needs	Roy McConkey and Rosario Baxter	2
Traumatic Brain Injury in Ireland – An Inclusive Rehabilitative Approach within the Community	Niamh Rowe	7
Believing in children's progress: Approaching Maria's education	Eleni Tragoulia	10
Education for Children with PMLD in Israel	Naomi Ariel	14
After School	Edward Khasakhala	16
Project 'Shalom' in Lima, Peru	Jill Gramann	18
Personnel Working in PMLD in Australia	Sheridan Forster	20
Links with Holy Trinity School, the Philippines	Dominic Carey	22
The involvement of young people with learning disabilities in an international conference: moving beyond the factual to challenge our ideas on inclusion	Richard Rose	23
Persons With Profound And Multiple Learning Disabilities In Japan	Shigeru Suemitsu	26
The multifaceted condition and collective competence	Peter Limbrick	30
Future Focus: Sensory Experiences	Chris Fullerton and Di Foxwell	33
PMLD Network Email Forum: A Digest of Discussions (August – October 09)		34
News		38
Resources		40
Publications		41
Reviews		43
Short Courses and Conferences		44
Longer Courses (with accreditation)		50

GUEST EDITORIAL

Spring 2010

International Perspectives

This is a bumper edition and articles come from all over the world! Not everyone has been able to write about the group we describe as having PMLD in this country as that group either does not survive infancy or little is known about them in their own countries. Despite that we have 11 fascinating articles which we hope you will enjoy.

We start with countries close at hand with Roy McConkey's article from Northern Ireland about the development of integrated care pathways for children with complex physical healthcare needs. Then we cross the border to Ireland with an article from Niamh Rowe who works with people with acquired brain injury. Her article refers to more able people than those with PMLD as she explains, those with profound disabilities are not admitted to rehabilitation programmes.

We stay in Europe for one more paper, this time from Greece and written by from Eleni Tragoulia. She tells us about a young child with challenging behavior. Across the Mediterranean we call into Israel and hear about developing the curriculum for children from Naomi Ariel. We travel down Africa to Kenya for a paper from Edward Khasakhala who would love to write about PMLD but can only tell us what is NOT available for that group. He tells us a bit about a programme for young adults who are rather more able.

We travel west now to Peru and hear from Jill Gramann about a community project called Shalom. Next we set off across the Pacific to Australia to learn about a group of people who work with people with PMLD in different provinces. We go north now to the Philippines with an article written by Dominic Carey with support from Wendy Newby. Dominic is writing about a link his school in Gloucestershire has with a school in the Philippines.

Our world trip has three more stops. Richard Rose tells us of a conference in Singapore where people from many Asian countries gave papers relating to PMLD. The next stop is Japan with an article from Shigeru Suemitsu giving us very interesting insight into services in this country.

We come straight back to England for the last article. Peter Limbrick writes about some of the difficulties that can accompany providing multiple services for children with multiple needs. It reminds us that there is still much to do wherever you are in the world.

What a whirlwind tour! We hope you enjoy the trip.

Penny Lacey
Senior Lecturer in Education
The University of Birmingham

PMLD LINK Contacts

Subscriptions, information and enquiries

Carol Ouvry
31 Birdwell Road
Bristol BS41 9BD
Tel: 01275 394621
carol.ouvry@talktalk.net

Reviews

Di Foxwell
50 Boness Road
Wroughton
Swindon
SN4 9DT
di@phonecoop.coop

Production

Paul Bramble
The University of Northampton
Park Campus
Boughton Green Road
Northampton, NN2 7AL
Paul.bramble@northampton.ac.uk

Future Issues

Summer Vol. 22 No. 2 Issue 66 Sensory Experiences

Copy date
4th June 2010
Please send your contributions to:
Di Foxwell
di@phonecoop.coop
OR
Chris Fuller
fuller.chris@hotmail.com

Winter Vol. 22 No. 3 Issue 67 Lifelong Learning

Copy date
5th November 2010
Please send your contributions to:
Beverley Dawkins
Beverley.Dawkins@mencap.org.uk

ISSN 2042-5619

The development of an Integrated Care Pathway for services to children with complex physical healthcare needs

Roy McConkey and Rosario Baxter

Institute of Nursing Research, University of Ulster

Overview

This paper describes the development in Northern Ireland of an Integrated Care Pathway (ICP) that aims to span health services across the acute and community sectors along with linking social services, education and non-statutory provision. The Pathway was developed through an interactive consultation process led by a multi-disciplinary Steering Group and based on the findings from local as well as international research. It provides a template from which locally adapted Pathways can be developed.

The Concept of Care Pathways

An Integrated Care Pathway (ICP) has been defined as follows:

(It) determines locally agreed, multidisciplinary practice based on guidelines and evidence where available, for a specific patient/user group. It forms all or part of the clinical record, documents the care given and facilitates the evaluation of outcomes for continuous quality improvement.

However given the diversity of clinical needs within the focus population of children with complex physical healthcare needs, it was decided that the proposed Care Pathway would focus primarily on service procedures and activities relating to the overall care offered to these children and families, as per the Pathway developed by the Association for Children's Palliative Care (2004). However it was recognised that *clinical* pathways relating to a child's specific conditions should be linked to this care pathway as required.

An ICP can be developed to cover services within a country or region but often these need to be further adapted for more local circumstances. The agreed Pathway will guide the delivery of services across all providers – statutory and non-statutory – and should also embrace those arranged by families and funded by Direct Payments.

The ICP is a document that is available to families as well as the wider public to describe what they can expect from services. However this may need to be made available in a more accessible format than that provided to professionals. Once the content is agreed, this version can be prepared as part of the implementation phase of the Pathway.

Principles for the development of Integrated Care Pathways

Past experience suggests that the following are key to the development of ICPs (ACT, 2004).

- They must be developed and 'owned' locally by a multi-disciplinary team.
- They cross organisational and inter-agencies boundaries.
- They make the patient the focus of all the care planning and allow for variation when appropriate.
- They incorporate evidence- or research-based standards and guidelines.
- They include systems for rigorous record-keeping.
- They include measurement of outcomes and promote continuous quality improvement.

These principles have informed the development of the present Pathway although in some instances only in an initial way. For example to date it has not been possible to describe or test the measurement of outcomes or systems for rigorous record keeping although these are proposed within the Pathway. However all the above principles must be considered during the implementation phase.

Process for developing the Integrated Care Pathway

A multi-agency Steering Group was recruited to guide the development of the ICP for children with complex physical healthcare needs in Northern Ireland drawn from nursing, medical, education and social services along with parental involvement. The initial draft of the proposed regional ICP drew on research data gathered from Northern Ireland service personnel and parents during the first phase of the project (McConkey, Barr and Baxter, 2007). This information was further validated by research and development work conducted elsewhere (Kirk and Glendinning, 1999; Noyes, 1999; Abbott et al, 2005).

The following iterative process was followed for developing the ICP.

- The Project Steering Group first scoped the outline structure and content of the Pathway.
- The Project Staff developed a consultation draft of the Pathway based on research findings for further discussion with the Steering Group.
- The revised draft of the ICP was sent to a range of agencies, professionals and stake-holder groupings from across NI for their comment.
- The proposed Pathway was submitted for peer-review to two colleagues in England who were involved in the development of services for this client group.
- A further revised draft was discussed with the Steering group prior to its submission to the Department of Health who approved its distribution to health and social service agencies for them to embark on local implementation.

Content of the Pathway

The Figure illustrates the main strands and the sub-sections within the ICP. These are fully described in an accompanying booklet which is available on request from the first author¹.

Strand U represents the universal services that will have been involved to some extent in the care of the child either prior to admission to hospital or to whom the child is referred on discharge. However it is the interfaces between these Universal services and the specialist provision described in Strands 1 to 3 that are covered by the ICP. Of course a service framework that covers all children, such as the National Service Framework for Children and Young People and Maternity Services produced for England (Department of Health, 2005), helps to define the full details of this ‘Universal strand’ and the contribution these services could make to the generic care of children with complex physical healthcare needs and to their families.

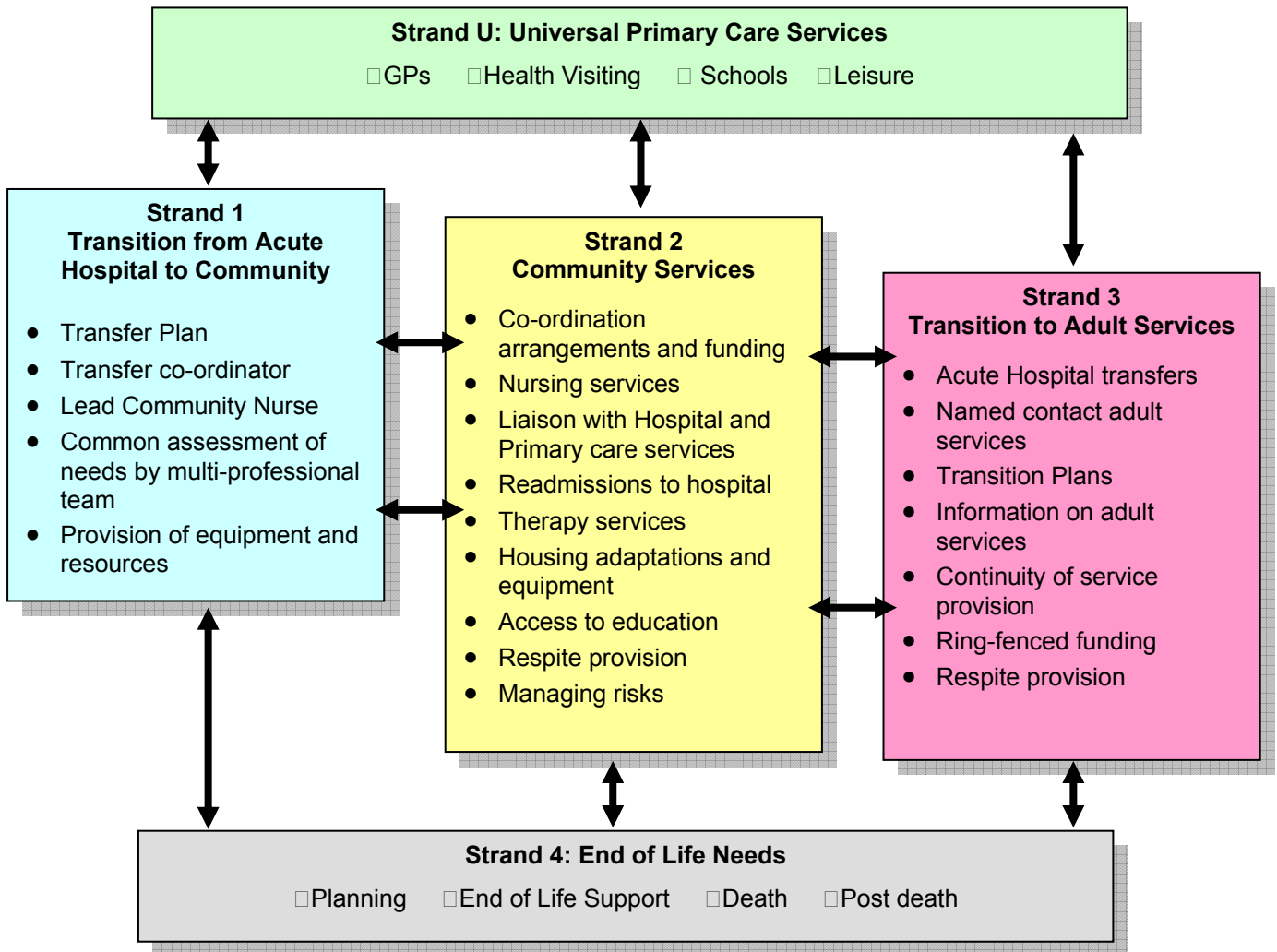


Figure: The content of the four main strands to the Integrated Care Pathway for children and young people with physical healthcare (PHC) needs

¹r.mcconkey@ulster.ac.uk

It is presumed that the child and family will enter this specialist Care Pathway from the acute hospital, although this may not always be so. The child's stay in hospital could be of varying lengths of time and may result from a condition that is present from birth or the result of a trauma in later life.

It is possible that the child may be transferred from a Regional Hospital Unit to an Area or District Hospital. The inter-hospital transfer arrangements are not specifically dealt with in this ICP although many of the points of good practice listed under transfer to community would apply in these circumstances. However re-admissions to acute hospitals from the community are covered under Strand 2.

Strand 1: The first strand of the ICP covers the transfer from hospital to community services. This is a crucial phase in the life of the child and family and handled successfully will contribute greatly to the family's confidence and their trust in services.

Strand 2: describes the community services available to the child and family. These would usually cover the chronological age range from birth to the child's 18th birthday. This strand entails a range of provision as the sub-sections indicate although not every child and family will need or want all the possible services.

Strand 3: outlines the transfer arrangements to Adult services. This aspect of services is the more poorly developed at present; partly because of the relatively few children who have required this strand of the

Care Pathway to date, but the numbers will rise in the future as their life expectancy increases. A Care Pathway for Adult persons would also greatly assist the transfer process but awaits development.

Strand 4: Much of the content of this strand has been taken from the Care Pathway produced by ACT (The Association for Children's Palliative Care: 2004) that covers End of Life and Bereavement. This strand of the pathway could be entered from any of the previous three strands and staff need to be prepared for this to happen.

The four different strands are related to one another as the arrows indicate. Actions listed under one strand may have to be commenced under an earlier strand. However for clarity they have been grouped under the strand in which the desired outcomes are listed.

Key Standards

The ICP contains four Key Standards relating to community services, one for each strand of the Pathway and these are summarised in Table 1 below.

Key Outcomes and Actions

Each strand also contains a listing of the key outcomes that should be attained within each strand of the Pathway and a Table is provided of the key actions required to attain these; an example of which is given in Table 2. These actions are grouped thematically as per the listings given in the above Figure.

Table 1: The key standards included in the Integrated Care Pathway

Strand	Standard
Strand 1: Transition from Acute Hospital to Community	Every child, having been assessed as having complex physical healthcare needs in the hospital setting, should have an agreed transition/discharge plan involving the hospital, community services (both universal and specialist) and the family. The resources required at home should be provided before the child leaves the hospital or as soon as possible thereafter.
Strand 2: Community Services	Every child and family should have a multi-agency support plan agreed with them for the delivery of co-ordinated actions to meet their individual needs. This plan should be regularly reviewed. They should be facilitated to enjoy a good quality of life as a family
Strand 3: Transition to Adult Services	Every child and family should have an agreed transfer plan to adult services in both acute hospital and community services, and no loss of needed service should be experienced as a result of the transfer.
Strand 4: End of Life Needs	Every child and family should be helped to decide on an end of life plan and should be provided with care and support to achieve this as closely as possible.

In the final version of the Pathway at a local level, a named agency and person is assigned responsibility for the implementation of the action. In the present draft of the Pathway, indicative persons/agencies are noted. The essential contribution of the ICP is therefore to specify the actions to be taken and name the person or agency responsible for them.

Recording actions

The key outcomes and actions within each strand provide the basis for a pro forma that can be used to record the services provided to the child and family; any deviations (e.g. omissions/ improvements that occurred) and the reasons for them (see Table 2).

Table 2: Listing of Key actions for Nursing and other personal support services with Strand 2: Community Services

Responsibility and name of lead	Action Step	Details of Action taken with dates	Reasons for deviation
HSC Trust	Each child/family should be allocated to one nursing team who co-ordinates all inputs from nursing services in the community. (Presently a variety of nurses may be involved with the one child and family.) This nurse will liaise with the family health visitor.		
HSC Trust	A funded out-of-hours, on-call service (e.g. up to 10.00 pm) by community nurses for children with complex physical health needs should be provided throughout Northern Ireland. HSC Trusts should assess whether it is required in their area.		
Community Nursing/ Acute	Opportunities should be made available to nurses within acute and community settings (e.g. CNLD, district nurses) to develop additional knowledge and competencies in working with children who have complex physical health needs, and in supporting their families.		
Community Nursing/ Acute	All nurses should be inducted and mentored in the provision of nursing services to the children to whom they have been allocated, including relief and bank staff. A robust training plan needs to be in place involving acute hospital staff if appropriate. Evidence-based practice should be followed, e.g. contained in relevant care pathways for the particular condition if available ² .		
Community co-ordinator	The emotional and social needs of the child or young person are constantly reviewed and opportunities provided for them to have their needs and aspirations met, including referral to specialist help if required.		
Community co-ordinator	The health and emotional well-being of the parents and siblings is regularly reviewed. Carers of the child/young person are given advice and support. Referrals are made for more specialised support if needed.		
Community co-ordinator	Parents are directed to sources of financial advice and information about social security benefits; mobility allowances etc.		
Social Worker	Carers are offered an assessment of their own needs separately from an assessment of their child's needs.		
Social Worker	Carers are given the option of receiving Direct Payments.		

² The Contact a Family organisation has a useful directory of rare conditions that can assist practitioners in accessing information in a family-friendly format. <http://www.cafamily.org.uk/about.html>

In the main qualitative descriptive information is sought.

These records are a crucial tool in sharing information with families and across professionals as well as providing a means of further developing the ICP (de Luc, 2001). In time, it would be possible to specify more explicit criteria regarding service responses that could be used for auditing purposes, e.g. time limits within a response is made.

However the records relating to the ICP could mean a lot of record keeping is involved for each child. This would be handled more efficiently if the forms were completed electronically, which could be readily done through downloading them from an Internet site or being available on a CD-Rom. Copies also need to be held by the family. These issues should be addressed as part of the implementation plan.

Implementation of the Pathway

The development of the Care Pathway through a multi-agency consultative process completed Stage 1 of the process. The second stage is the implementation of the Pathway with the client group. Here the focus is on the use of documentation to gauge the variations that arise through parental choice, client needs and professional judgement that were not included in the interim ICP. This stage would assist in the identification of specific measures that could be used to audit service performance as well as testing suitable recording systems.

The engagement of other agencies at this stage (such as schools and adult services) may also lead to further revisions. A revised ICP should emerge from Stage 2 which is then implemented across the participating agencies.

The final stage of the process - Stage 3 - involves the ongoing review of the ICP so that there is continuous improvement in the delivery of care both locally and regionally. Mechanisms for doing this should include contributions from all stake-holders, for example as per the first phase of the present project.

Conclusions

Stages 2 and 3 fell outside the scope of the current project and are presently ongoing within selected areas. The complexities of multi-agency working are well recognised (McConkey, 2007) but as yet there are few examples of practical means for overcoming the many barriers to it. ICPs alone are not the solution but they do provide a catalyst for bringing together professionals from various disciplines and agencies to work alongside parents. Moreover it offers them all a common means of communicating about how the needs of the child and the family will be met. In sum, no mean

achievement for a simple booklet that outlines what all the stake-holders agree is best practice.

Contact details

Roy McConkey
r.mcconkey@ulster.ac.uk

References

- Abbott, D., Watson, D. and Townsley, R. (2005) The proof of the pudding: What difference does multi-agency working make to families with disabled children with complex health care needs? *Child and Family Social Work*, 10, 229–238
- Association for Children's Palliative Care (2004): *Integrated Multi-agency Care Pathways for Children with Life-threatening and Life-limited Conditions*. Bristol: ACT.
- Department of Health (2005) National Service Framework for Children and Young People and Maternity Services. London: Department of Health.
- Kirk, S. and Glendenning, C. (1999) *Supporting Parents caring for a Technologically- Dependent Child*. Research Report: National Primary Care Research and Development Centre, University of Manchester.
- McConkey, R. (2006) Multi-agency working: An excuse for inaction? In J. Forbes, (ed.) *Service integration in Scottish Schools: Values, vision and vital voices*. Aberdeen: University of Aberdeen (School of Education).
- McConkey, R., Barr, O. and Baxter, R. (2007) *Complex Needs: The Nursing Response to Children and Young People with Complex Physical Healthcare Needs*. Belfast: DHSSPS.
- Noyes, J., Hartmann, H., Samuels, M., Southall, D., (1999) The experiences and views of parents who care for ventilator dependant children. *Journal of Clinical Nursing*. 8, 440-450.

Traumatic Brain Injury in Ireland – An Inclusive Rehabilitative Approach within the Community

Niamh Rowe
Rehabilitation Vocational Specialist, Dublin

As a result of the development of medical science the mortality and morbidity caused by Traumatic Brain Injury (TBI) has reduced (Philips Report 2008). However, as a result of such improvement in hospital medical services, the reduction in figures can also aid to mask as highlighted within the Philips Report (2008) the long term effects of TBI for the individual and their family. This concept is further emphasised by the Trauma Audit and Research Network (2006) who note how for every TBI death at least two other people survive with permanent disability. The Philips Report (2008) was research carried out over a two-year period in Ireland. The subject matter was on epidemiology and demographics of TBI. The Department of Health and Children funded the project which brought valuable and yet worrying statistics. One such statistic is how within the Republic of Ireland, TBI is considered to be the main cause of premature death. Following on, the majority of TBI in Ireland is due to falls (59% of all injury) and more than a third of injuries occur in the home. Even though the Philips Report has brought us much needed information on TBI within Ireland, it did however have some limitations. The report only focussed on the early acute hospital setting and the events leading up to the injury. It did not address the patient's entire injury, their progress should they require long-term hospitalisation to an individual's transitional rehabilitation out into the community. It is at this stage of community rehabilitation that I would now like to present, as this is an area that I currently work in and have a personal interest and passion for.

Neurosurgical service units

Initially, all TBI cases are referred to either of the two Neurosurgical Service Units (NSU). The national unit is located in Dublin, called the Beaumont Hospital, while in Cork, there is the Cork University Hospital. Both of these centres provide in-patient care and a telephone based neurosurgical advice service (NAS) for both traumatic and non-traumatic illness. Following the patients discharge from the hospital is where the system can fall down. Over my years of working within the area of Acquired Brain Injury (ABI), many individuals and their families who have been referred to our service often note how it was by chance that they heard about our programme, often waiting years post-injury before accidentally coming across our service.

My role

I work as a Rehabilitation Vocational (RV) Specialist within a charitable organisation which runs different services for people with an ABI. One such service is the Rehabilitative Training Service in which I have worked for the past eight years. During this time, I have completed an MEd and am currently completing my PhD, where my research continues to focus on the needs of those with an ABI. The RV Specialist takes on different roles surrounding aspects of rehabilitation. The first role caters towards the educational and awareness needs of the individual through the design, development and delivery of classroom module based training. Following on, my role also adopts a consultative supporting role, acting as a designated keyworker

for clients and their families. Within this role, I would work with the individual and their families in the development and implementation of a supported person-centred Individual Training Plan (ITP). The aim of the ITP is to address and facilitate the needs of the clients, catering for their physical, emotional, behavioural and cognitive needs. Finally, my job also involves raising awareness of ABI out into the community amongst other disciplines, for example: General Practitioners, Primary Care Teams and other voluntary bodies.

Programme approach adopted

Applying relevant, appropriate techniques and structure for people with an ABI is vital to the development and continuous fulfilment of the individual. One such approach of improving the success of learning within a rehabilitative setting is the concept of Inclusion. Over the years, the service provider I work for has explored different inclusive approaches. Within the setting I work in, we adopt a phased inclusive method approach. In developing this practice further, our current rehabilitative training programme is based within a mainstream further educational setting, which supports the gradual transition (if applicable) of clients into a complete mainstream environment. Furthermore, we could take this concept further by possibly saying that the existing rehabilitative programme works to the Mencap (1999) promotion of Inclusion by running a specialised school within a mainstream school. I feel at this stage it is important to note how this form of partnership is the only such existing partnership

within the Republic of Ireland and has been in existence for over ten years. Ultimately, the partnership's aim of the inclusive rehabilitative approach is to provide a meaningful, manageable and relevant curriculum through utilising different teaching and learning strategies within a collective partnership module.

Details of the programme

The programme is based in Dublin within a College of Further Education and runs full-time for two years, from Monday to Friday. The programme is partially funded by the Health Service Executive (HSE) and is monitored regularly to assess its feasibility.

The modules covered range from core modules surrounding: *Brain Injury Education* which includes the identification and development of *Compensatory Strategies* to the *exploration of Activities of Daily Living*. Such classes promote an increase in the client's levels of awareness and acceptance of their ABI. The importance of facilitating the awareness and acceptance levels of the individual with an ABI is seen by Oddy, Coughlan, Tyerman and Jenkins (1985) who notes how awareness difficulties can lead to impaired psychological functioning and is considered to be one of the major problems in long-term rehabilitation of people with TBI. Furthermore, when supporting the client's levels of self-awareness, the staff consider thoughts from Prigatano and Altman (1990) who suggest that we take a holistic approach and explore all elements, for example: the family, the individual with the TBI and neurological assessments to see how they may play a vital role in the impairment of self-awareness.

Another core module is *Personal Development*, where its importance flows across the board from within the classroom to the individual's one to one activities. The focus of this module surrounds the importance of addressing the need to restructure the self-esteem of the individual following an ABI. The need to facilitate and address an individual's self-esteem level following a TBI is vital to their rehabilitation as many individuals' self-esteem levels change, resulting in loss of their own worth, abilities and capabilities. This concept is postulated by Groswasser, Melamed, Agranov and Keren (1999), who outline the need to focus on raising an individual's self-esteem levels, following a TBI, in order to maximise their overall recovery and rehabilitation.

Furthermore, an individual's experiences of success and failures as emphasised by Crocker and Wolfe (2001) can cause an individual's self-esteem levels to fluctuate on a daily basis. To address such a concern, the staff would recognise and promote the need for ongoing support to be given to the individual and indeed their family in order to

encourage sustainability of the newly acquired self-esteem level. Such method of promoting and maintaining the level of self-esteem is adopted through different modules running within the programme. One such module is the Drama module, which is delivered by a college teacher and co-facilitated by a staff member. Improvisation and role play techniques are utilised by the group to ensure no pressure is placed on the group surrounding their short term memory. The module also acts as a tool to develop the group's "oracy skills" as well as boosting their esteem levels by receiving positive feedback from their audience after presenting plays to their fellow mainstream college students during the year.

Other modules the programme runs, all of which have the central theme of supporting the need to restructure self-esteem within the rehabilitation process, are: Food and Cookery, Music Appreciation, Computers and Work Preparation. The Further Education and Training Awards Council (FETAC) nationally accredit some of these teacher driven classes.

Aims of the programme

The central theme of the programme is to promote early access of clients to the rehabilitative service following their hospital discharge stage. Each year of the programme has different aims and focuses. The first year mainly centres on the development of an understanding and acceptance of the ABI with the clients and their families. During this year, the designated keyworker works closely with the client and their family in identifying the individual's personal and training goals within an ITP.

Such development of support and awareness takes place through different channels. One such form of support is through the development of a peer support structure within the group. This is partly achieved through the attendance of classroom-based training whereby open discussion and shared learning is practiced. Many clients feel that the running of group sessions allows them to bond and make friends, whilst also supporting them in sharing their own inner feelings and emotions within a safe environment.

Another channel of support and raising awareness is through the integration process of the programme. Within the current further educational setting, clients have the opportunity to mix with their own age and make friends thus enhancing a sense of belonging, which is important for self-value. This act of integration is also seen to be two-fold as different groups over the years have ran Acquired Brain injury awareness talks within the college to raise awareness of what Simpson, Simons and McFadyen, (2002) refer to as a hidden disability.

Finally the second year of the programme focuses on the development of a transitional plan. Different routes and options are collectively explored, for example: the need to support the development of a scheduled week plan, the seeking of voluntary work to paid employment. It is also possible due to the existing partnership we have with the college, that clients may wish to be supported in their transition into mainstream academia and become totally integrated into the college.

Further development

After working in an inclusive setting for rehabilitation, I personally feel that the concept of Inclusion should be explored further within Ireland. The exploration could adopt a positive move within the educational rehabilitative setting and can, once implemented aid the development of the individual with an ABI. However, I also note as emphasised by Norwich (2000) the importance of identifying different levels of Inclusion in order to promote the correct level for each student depending on their individual needs and strengths. This is ever more evident when clients move into the mainstream setting within the college and require additional time and staff. Such needs can place the educational system under financial strain. So whilst Inclusion is a positive concept, it can have a detrimental effect on existing educational set-ups if careful planning, funding and additional resources are not available.

Following on, since ABI is lifelong, there is a need to develop ongoing supportive services for clients and their families post their two year rehabilitation time. Support has been given to the family and the client for two years. It is therefore unethical to cut such a support after their time on the programme has ceased. However, the time and work demands placed on staff can cause barriers as staff are pulled between their work commitments of their existing clients to the need to provide ongoing support to those who have ceased attending.

Finally, there is a need as emphasised within the Philips Report to promote more awareness of the effects of an ABI in order to develop a more diversified multi-disciplinary service team out in the community. Such a development of awareness and education may go towards aiding and supporting the client and their family post rehabilitative time out in the community.

I would welcome discussion surrounding this article either through e.mail at: niamh_rowe@hotmail.com or by post at Niamh Rowe, C/O Colaiste Ide, Cardiffsbridge Rd, Finglas, Dublin 11, Ireland.

Contact details

Niamh Rowe
niamh_rowe@hotmail.com

Bibliography

- Crocker, J., and Wolfe, C.T. (2001). Psychological Review, 108. p593-623. *American Psychological Association*.
- Groswasser, Z., Melamed, S., Agranov, E. and Keren, O. (1999) Return to Work as an Integrative Outcome Measure Following Traumatic Brain Injury. Vol 9, Numbers 3-4, pp 493-504. *Neuropsychological Rehabilitation*, Psychology Press.
- Mencap (1999) On a Wing and a Prayer: *Inclusion and Children with Severe Learning Difficulties* London: Mencap
- Norwich, B. (1997) Exploring the perspectives of adolescents with moderate learning difficulties on their special schooling and themselves: stigma and self-perceptions, *European Journal of Special Needs Education*, 12, 1, 38-53.
- Oddy, M., Coughlan, T., Tyerman, A, Jenkins, A. (1985). Social adjustment after closed head injury: A further follow-up seven years after injury. *Journal of Neurology, Neurosurgery and Psychiatry*. pp. 48, 564-568
- Philips Report. National Traumatic Brain Injury in the Republic of Ireland. (2008) Traumatic Brain Injury Research Group. pp. 1,6,13,33,59
- Prigatano, G.P. and Altman, I.M. (1990), Impaired awareness of behaviour limitations after traumatic brain injury. *Archives of Physical Medicine and Rehabilitation*, 71, 1058-1064
- Simpson, G., Simons, M. and McFadyen, M. (2002). The challenges of a hidden disability: Social work practice in the field of traumatic brain injury. *Australian Social Work*, Vol 55, Issue 1, pp. 24 – 37. Blackwell Science Asia Pty. Ltd.
- Traumatic Audit and Research Network <http://www.tarn.ac.uk/content/images/53/overview%2006.pdf>

Believing in children's progress: Approaching Maria's education

Eleni Tragoulia
Teacher in Crete

In this article emphasis is placed on the positive side of the education of children with profound and multiple learning difficulties (PMLD) by describing the way education was approached for Maria, a 5 year-old girl who presented PMLD and was educated in a Greek special setting. The discussion arises from the results of an action research (Elliot 1991) which took place in a multidisciplinary school and aimed at changing perceptions on the education of children who present PMLD through a common interdisciplinary approach (Lacey & Ouvry 1998, Lacey 2001). In this way it is shown that under specific circumstances, intervention can be organised and can lead to an effective education without, though, disregarding the difficulties which exist in Greek educational, social and political levels.

The setting

In Greek educational contexts, educating children who present Profound and Multiple Learning Difficulties is an area relatively new and so are the strategies and the programmes to be followed (Lampropoulou & Panteliadou 1995) even though the new legislation made the education of all children who present special educational needs obligatory (Law 3699/2008). Consequently, even though in other countries the importance of educational provision for children who present PMLD is undoubted (Ouvry, 1987, Ware, 1994), in Greece the views and perceptions are not supporting the education of children with PMLD and thus their deconstruction are of immediate need. The presented action research lasted from October 2000 until June 2003 and took place in a children's centre in the mainland of Greece which provided therapeutic and educational programmes for children who presented severe to profound learning difficulties. The centre consisted of 6 main departments: Physiotherapy (15 therapists), Occupational therapy (12 therapists), Speech therapy (6 therapists), Psychology (2 psychologists) Education (3 teachers and 6 learning support assistants) and the Neurological or Medical department (5 doctors). My initial purpose was to create an inclusive teaching environment by shifting the dominant views on the education for children who present profound and multiple learning difficulties. It was by then obvious that the Greek educational system, as all educational systems in other countries, should no longer disregard the needs of the children who present profound and multiple learning difficulties and should place importance on their education (Lacey 1998). Unfortunately, by that time Greek reality had showed that the education of children who present PMLD was regarded as a 'problem' referring to the families and not to the wider social community (Bjarnason, 2008). The deconstruction of the

prevailing attitudes was of immediate change. To this change the research was focused on, by organising the education of Maria, a 5 year old girl who presented PMLD and was regarded by the professionals not able to be educated and included in her school environment.

Maria

Maria is a 4 year old girl who lives with her parents and is the only child in the family. She is defined as presenting multiple difficulties and challenging behaviour. She started attending a set of therapeutic sessions in the researched setting when she was 6 months old. At the age of three she was integrated into the educational department where she could attend the educational programme in a parallel way with the therapeutic sessions. Maria was regarded by most of the professionals who were in contact with her, as a child who cannot develop a reciprocal communication with either the adults or her peers. When she was in the class, she remained a passive member towards the educational process, absorbed in a series of stereotypical, repetitive and self-injurious movements (biting her hands, grinding her teeth, flapping her hands/ tapping her feet/ flickering her eyes/ making loud sounds). Her physical situation did not permit her to walk; however she was quite able to sit unsupported, roll, reach and hold things. She did not use oral speech and seemed to have great difficulty in finding a way to express her needs. She avoided eye-contact and presented tactile defensiveness. Maria was defined as a child who presented profound learning difficulty with an additional demonstration of challenging behaviour. The biggest problem that Maria confronted was her difficulty to communicate her needs, desires and problems. In this way it became very difficult for her to become understood and develop relationships with the people she meets.

The views on Maria's education

The views of the different professionals working in the context were explored in order to locate the reasons for which Maria was completely excluded from the educational activities. Thus, some representative statements are given below.

Occupational therapist Maria does not collaborate so her assessment is difficult. She does not accept any way to play so I can't do anything as she does not help me.

Physiotherapist: Maria does not collaborate so her assessment cannot be done properly. She is not playing so as to use games in order to assess her. I cannot do a lot because she is not helping me.

Physiotherapist: Maria's situation remains severe, she observes better; the stereotypical behaviour continues, She says some words but not understood.

Physiotherapist: She says some words but these are not easy to not understand

Neurologist: The child does not do things; she has autistic elements, she looks vaguely and flickers her eyes. My impression is that she has mild Cerebral Palsy but with severe intellectual disability and sensory problems especially sight as well as second degree behavioural problems. I do not know if she benefits by the educational programme.

Psychologist: Maria was integrated in the educational programme because of social reasons (poor family/ no other context to accept her) because her behaviour and profound intellectual disability would not allow her to follow the educational programme

The complexity of Maria's needs was such a barrier that the professionals in the setting were persuaded that she could not be educated and that she belonged to another 'more specialised' setting by transferring the responsibility to the child. It was apparent that exclusion happened in a special setting and the professionals expressed the reasons all referring to Maria's difference in relation to her peers. The fact that she presented PMLD and not severe learning difficulties was the reason she was excluded by all educational activities. It was obvious that the professionals could not see Maria as a student. The views stated by the professionals could not change in any other way but by organising an intervention program which would prove that Maria could respond to an effective educational program despite the complexity of her needs.

Maria's educational program

Before organising an intervention program, Maria was closely and systematically observed. It appeared that she was feeling helpless as she had no tools to communicate her needs at home or at school. This helplessness was attributed to a great extent to the fact that Maria's needs could not be understood by the people involved in her life. Furthermore, her physical impairment was further reinforced by the demonstration of challenging behaviour and specifically the self-injurious behaviour. As Maria could not interact with the environment (physically or socially) self-injurious and repetitive behaviour has been a source of stimulation with the clear consequence of isolation (Murphy et al 1993). Moreover the tendency of the people who were in daily contact with Maria to limit her behaviour as well as their reluctance to believe in her progress was experienced by the child as a punishment and was leading her to feel sad and rejected by her surroundings. Maria was completing a self-fulfilling prophecy for a long period of her lifetime.

Furthermore, Maria was in great need of receiving affectionate behaviour from the adults as it was evident by the contact with her parents that her family seemed unable at this time to offer caring and affectionate behaviour (Bee 1997).

An intervention programme was organised in order to cover the real needs of the child. The application of Makaton symbols in the teaching process became the means in order to increase Maria's understanding of the process and to provide her with alternative tools to develop her communication skills. The use of Makaton symbols was not introduced as a narrow, inflexible communication strategy without taking into consideration how Maria could use them (Duncalfe 2005). Rather it was introduced alongside activities integrating pictures, sensory work and body and hand expressions. The integration of the Makaton programme was based on the assumption that Maria could not understand verbal instructions which led her to experience confusion and anger; the Makaton symbols were thought to assist in advancing Maria's understanding of the processes she was daily involved in.

As it was well realized that Maria needed to receive affectionate behaviour from the people involved in her life because as previously stated, she seemed to be feeling rejected by her school and family environment. Thus the program additionally involved elements in the programmes which would assist Maria in feeling accepted and loved. The programme was named 'love programme'. Within this programme we tried to promote caring as a priority which would then lead to the formulation of a relationship with Maria based on mutual trust and close bonding. Trust and bonding were deemed significant elements for the progress of all children

independent of age, disability or gender (Riele 2006) and were particularly emphasized in our praxis. This emphasis was not new: it was based on the principles of interactive approaches (Collis & Lacey 1996) and Gentle Teaching (McGee, Melnolascino, Hobbs & Menousek 1987), programmes which were applied after locating the real needs of the child.

The results

The intervention program led to the deconstruction of the prevailing view, that children who present PMLD cannot progress or develop reciprocal relationships (Ware 2003). The introduction of Makaton symbols in the teaching process increased Maria's understanding by widening her vocabulary and Maria reached the point where she could communicate her immediate needs. The affectionate behaviour shown by the adults functioned as a release of stress for Maria as she felt loved and accepted. Maria kept on presenting PMLD but she was no longer regarded as a child unable to be educated and excluded by an educational system.

Discussion

The assessment of the intervention programme led to the realisation that the views on the education of children who present PMLD adopted by the therapists and the existence of the medical model were leading the professionals to disregard the needs of the child and underestimate the value of being educated. This in combination with the lack of a theory which would support practice, something which is regarded as highly determinative in promoting effective teaching and learning, were believed to be the main elements that made practice dysfunctional. What was absent was a common vision and purpose amongst the various professionals which is believed to be the most beneficial outcome from the collaborative approach followed (Doveston and Keenaghan 2006). After the positive results of the programme all professionals believed in the value of Maria's education and had become enthusiastic to continue in the movement towards the improvement of her education. The professionals' involvement in the project assisted in acquiring a motive not only for the amelioration of the child's education but also for their own professional and personal knowledge (Watkins 2006). Even though the complexity of the needs of a child who presents PMLD indeed presents a challenge for each professional, however what is strongly recommended is to distance ourselves from the stereotypical picture the label PMLD is forming and see the child as a student with different needs which are never the same and can always be effectively approached and met.

Contact details

Eleni Tragoulia
etragoulia@yahoo.gr

References

- Bee, H. (1997). *The Developing Child*. New York, Longman.
- Bjarnason, D.S. (2008). Private troubles or public issues? The social construction of "the disabled baby" in the context of current social and technological changes. In S.L. Gable and S. Danfort. (eds.) *Disability and the politics of education: An international reader*. N.Y. Peter Lang Publisher.
- Collis, M. and P. Lacey (1996). *Interactive Approaches to Teaching : a framework for INSET*. London, David Fulton.
- Doveston, M. and M. Keenaghan (2006). Improving Classroom Dynamics to Support Students' Learning and Social Inclusion: a Collaborative Approach. *Support for Learning* 21(1): 5-11.
- Duncalfe, K. (2005). Creative Communication. *PMLD Link* 17, No 3(52): 16-17.
- Elliot, J. (1991). *Action Reseach for Educational Change*. Milton Keynes-Philadelphia, Open University Press
- Lacey, P. and C. Ouvry (1998). *People with Profound and Multiple Learning Disabilities: a Collaborative Approach to Meeting Complex Needs*. London, David Fulton.
- Lacey, P. (1998). Multidisciplinary Teamwork. Promoting Inclusive Practice. In C. Tilstone, L. Florian and R. Rose. London, Routledge.
- Lacey, P. (2001). *Support Partnerships: Collaboration in Action*, London: David Fulton Publishers.
- Lampropoulou, V. and S. Panteliadou (1995). Inclusive Education: The Greek Experience. In C. O'Hanlon *Inclusive Education in Europe*. London David Fulton Publishers.
- McGee, J., F. Melnolascino, D. Hobbs and P. Menousek (1987). *Gentle Teaching: A Non Aversive Approach to Helping Persons with Mental Retardation*. New York, Human Sciences Press.

Murphy, G., S. Hall, C. Oliver and R. Kissi-Debra (1999). Identification of early self-injurious behavior in young children with intellectual disability. *Journal of Intellectual Disability Research* 43(3): 149-163.

Ouvry, C. (1987) *Educating pupils with profound handicaps*. Kidderminster: BIMH Publications

Riele, K. (2006). Schooling practices for marginalised students - practice - with - hope. *International Journal of Inclusive Education* 10 (1): 59-74.

Ware, J. (2003). *Creating a Responsive Environment for People with Profound and Multiple Learning Difficulties*. U.K, David Fulton Publishers.

Ware, J. (1994). *Educating Children with Profound and Multiple Learning Difficulties*. London, David Fulton Publishers.

Watkins, A. (2006). So what exactly do teachers-researchers think about doing research? *Support for Learning* 21(1): 12-18.

Have you sent your subscription for 2010 yet?

If you have forgotten to send it please do so as soon as possible so that your details can be updated on the mailing list ready for the Summer issue.

If your details have not changed you can just send a cheque with your name and address. No need for a form.

If your details have changed or you are a new subscriber, please use a form – you will find one at the end of this issue.

Summer Vol. 22 No. 2 Issue 66

- Sensory Experiences -

The copy date for all articles, information and news for the Summer 2010 issue is the 4th June 2010

Please send contributions to:
Di Foxwell
di@phonecoop.coop
Or
Chris Fuller
fuller.chris@hotmail.com

Summer Vol. 22 No. 3 Issue 67

- Lifelong Learning -

The copy date for all articles, information and news for the Winter 2010 issue is the 5th November 2010

Please send contributions to:
Beverley Dawkins
Beverley.Dawkins@mencap.org.uk

Articles can be long or short and they are welcomed from carers or professionals alike – we value YOUR experience and views. Please contact us if we can help you in any way. If you have any pictures or photos to include we would love to see them (providing we have permission).

Education for Children with PMLD in Israel

Naomi Ariel

David Yellin Teacher Training College, Jerusalem

I am a teacher educator in David Yellin Teacher Training College in Jerusalem, Israel and for the last five years I have also been doing in-service training for teachers working with pupils with PMLD.

Here in Israel we are at the stage of taking the National Curriculum core subjects and adapting them to the PMLD population. We are also trying to develop a “user friendly” IEP for pupils which is a working tool for the multidisciplinary team together with the parents. We are clearly a number of years behind your experiences in the UK.

Background

The first Special Education Law was passed in Israel in 1988, stating that children between the ages of 3 and 21 should receive free special education in the least restrictive environment and that at the beginning of each school year a multidisciplinary team must prepare an IEP. In 2002, a clause promoting inclusion was added to the law. In theory we have a spectrum of placement options from a special school through to inclusion in a regular classroom with a learning support assistant. I personally am not aware of students with PMLD being included all day in a mainstream classroom. According to the most recent figures from the Ministry of Education (2009) there are only two classes of pupils with complex difficulties and moderate cognitive disabilities in mainstream schools in Israel. As a result of the report of a public committee that was set up to check the special education system in Israel (The Dorner Report, 2009) a proposal for a new Special Education Law has been put forward. This will give parents and the child the right to choose their educational placement and the child will receive a “basket” of special educational services according to his disability and function. If this law goes through it will most certainly lead to more inclusion.

Curriculum for PMLD Pupils in Israel

It is only during the past five years that PMLD pupil's educational needs have really been addressed and their right to access a variety of subjects like any other pupil. Beforehand our work was based on the medical model with an emphasis on providing therapies and attending to their physical and medical needs. The driving force was the therapists in the PMLD programmes with it being questionable what the teachers role was. We have moved on now and the teachers are leading the multidisciplinary teams with lots of talk of teaching subject matter. There are still therapists who are finding it hard to adapt to the collaborative approach and to the idea that the goals are the pupil's goals, not their own professional goals. We are still struggling with defining functional goals for our PMLD pupils and are grappling with the

integration of the pupils' IEP goals into the class program. We have to try to get to a state of equilibrium between the therapists and teachers so that the core subjects are used as a means to improve and practice skills throughout the day. We need to see less pull out therapy and an emphasis on meaningful learning in natural settings. It is not yet clear how to do this effectively and we have not reached the point where we are consistently using assessment tools or monitoring pupil's progress. This is probably not helped by a lack of a national inspection service to monitor the work in our special schools.

In 2007 the Department of Special Education issued guidelines that state that special schools have to base their curriculum on the curriculum in mainstream schools with the appropriate accommodations, modifications and alternatives. The core curriculum for special schools includes; Life skills, Language, Mathematics, Computer, science and technology, Citizenship, the Arts and Sport. We are presently trying to develop an integrated model to teach these core areas. In addition to this core curriculum, schools can develop additional programmes specific to the school population for example, Coping with Hospitalization or ADL. A big emphasis has also been placed during the last few years in developing standards for language and literacy skills and giving the PMLD pupils access to stories and books. This has been a major breakthrough and it is becoming more and more unlikely to find a PMLD classroom without sensory stories or a special school for pupils with SLD and PMLD without a library. Introducing the teachers and therapy staff to the idea that these pupils have the right to have access to many subjects like all pupils has without doubt opened up the opportunities for pupils with PMLD. We are seeing timetables in PMLD classes that include for example science, functional mathematics and literacy lessons. We now need to be wary to keep focused on the child and not the subject matter.

To the future

In my opinion, the two central challenges are firstly developing collaborative team work together with parents in individual, class and school programmes and secondly striving together to give our PMLD pupils the best quality of life and a curriculum rich with opportunities to experience the world, interact and connect with their environment.

Further information:

Gumpel, T,P & Meadan, H (2002) Special Education in Israel. *Teaching Exceptional Children*. May/June (pp.16-20)

The Dorner Report (2009) <http://meyda.education.gov.il/files/Owl/Hebrew/Dorner.pdf>

Special Education Law (1988) in English
Ministry of Education, Department of Special Education, Israel.
www.education.gov.il/special/english

Bizchut, the Human Rights Centre for People with Disabilities
www.bizchut.org.il

Contact details

Naomi Ariel
theariels@bezeqint.net

Mark Gray Associates

" for all your specialist communication training & sensory function assessment in PMLD" for details contact Mark Gray on 0115 9732540 web site www.markgrayassociates.com



After School, What?

Edward Khasakhala
Kenya Institute of Education, Kenya

I have been asked to write about PMLD in Kenya but I am afraid I can't write much so the majority of this article is about mental disabilities in general. In Kenya, people with profound and multiple learning difficulties rarely survive past infancy due to insufficient medical care. In the past a baby born with multiple disabilities in most communities in Kenya were not let to survive. For example in pastoralist communities they were smeared with ghee and exposed to strong sunshine until they die. Other communities living along the rivers used to throw these children in rivers. In other communities parents were advised not to allow the baby to suck and eventually the babies starved.

Presently, there is only one school in Kenya that has enough facilities to cater for the needs of children with multiple and profound learning difficulties. It is located in Nairobi and it is beyond the reach of many parents with these types of children.

In order to cater for their needs Kenya institute of Special Education has embarked on an intensive programme to train teachers for this group of learners. The first target has been teachers for children who are Deaf-Blind. The government has been able to set up several units for children who are deaf blind and one special school has also been established to serve these learners.

Several challenges face learners with mental disabilities in Kenya. The most serious challenge that faces these learners is transition from school to the community after the completion of formal schooling. This could be due to the type of education that is offered to these learners as most of the schools for learners with mental disabilities in Kenya are boarding schools which seem to be detached from community activities. As most of these learners go through the schools they are inadequately prepared for community integration. Most of them have inadequate skills in areas that are quite essential in community such as vocational skills, civic education, budgeting and activities of daily living.

It is against this backdrop that Ebusiratsi Special School came up with a community based rehabilitation programme to assist in the integration of learners with mental disabilities after formal schooling. Ebusiratsi Special School for Learners with mental disabilities started as a unit for learners with mental disabilities in 1986. It became a full fledged special school in 1998. It offers a specialist curriculum for learners with mental disabilities which consists of basic numeracy and literacy in the foundation stages. Learners are also taught functional academics and simple survival skills.

Part of the school's intervention strategy to de-

congest the school and make it more accessible to other new deserving students, the school introduced home based care programme currently the learners on home based programme are 42. They have gained skills in areas such as rope making, farming and simple business of selling firewood and vegetables. The students are visited once or twice a week by the teacher in charge of the home based programme who instructs the student together with the parent or guardian on vocational skills alongside other survival skills such as basic hygiene and cookery.

This programme aims at increasing awareness and support of the needs of people with mental disabilities. It is envisaged that through the project, there would be increased community awareness on the needs of people with mental disabilities, rehabilitation of this group of people, formation of parent support groups and increased capacity of parents/guardians and community to support people with mental disabilities. In the long run, it aims at enabling the community to be aware of the potentials of these people with disabilities and to protect and give them their rights. Along side these aims the school is also trying to mainstream HIV and AIDS as there is a misconception in the community that people with disability are HIV and AIDS free thus more people are sexually abusing them. The overall goal is to have enhanced participation of people with mental disabilities in community activities.

To assist the school to carry out this programme, the school recruited voluntary Community based Rehabilitation workers. These are individuals with some basic skills in the area of disability. They educate other community members on disability issues create awareness on disability and provide linkage with the school, community and the government. The parents/guardians of people with mental disabilities are members of this group.

Through the Community Based Rehabilitation group the level of awareness of disabilities in the community has greatly improved. The issues

regarding child's rights and prevention of HIV and AIDS have been intensified. There has been increased early Identification and Intervention of learners with special needs education in the community.

Case one

Jacob Otanga

Otanga is aged 31 years. He has mental disabilities and speech difficulties. He has fine motor problems gross body coordination. He has a slurred speech with a lot of blocks that one needs to devote much attention to the speech in order to get what he is speaking. His mother separated from his father when he was two years and was brought up by his father who was also having moderate learning disabilities. His father died in 2007. Otanga is now under the care of an aunt.

Otanga was among the pioneers of Ebusiratsi special school in 1986. He stayed at the school until 2005 when he was put on home based programme. The school gave him a local cow as he had shown much interest in looking after cattle.

Case 2

Grace Amukasa

Amukasa is aged 30 years. She stays with both her parents she joined Ebusiratsi Special school in 1996. She was put under the home based programme in 2005 and the school gave her a goat to start her Income Generating activity. In her pre vocational training, she acquired skills in knitting, gardening and weaving.

In her home based programme, she does knitting, selling of firewood and gardening and goat keeping. She has mastered the self care skills and can lead independent life with minimal supervision.

Challenges encountered

Several challenges are encountered by the school in implementing this home based programme.

- There is only one teacher for the programme who has also lessons to teach in the special school as such she has to visit the 42 learners in the afternoon.
- Transport due to poor road net work
- Lack of remuneration as all the CBR workers are volunteers
- Assumption by the parents and the community that the Home Based Programme is well funded thus they over expect financial support from home based programme teacher and the volunteer CBR workers.
- Lack of communication for example no telephone or mobile phones
- Lack of rehabilitation facilities and adequate vocational training in line with the advancement

in technology.

- Much work overload for the teacher and CBR workers.
- High level of illiteracy among the parents/guardians and community members.

Contact details

Edward Khasakhala
khasakhala@yahoo.com

Project 'Shalom' in Lima, Peru

Jill Gramann
Trustee for BILD

When one thinks of Peru from here in the UK the images conjured up tend to be tourist ones; Machu Picchu, Inca ceremonies, llamas, alpaca scarves and so on. Yet for most Peruvian these are as distant as they are for us.

Buenos Milagros [great miracles] is a very poor district of Pamplona Alta, Lima. It is a shanty town of make-shift dwellings built on hills on sandy, grey rock, and forms part of the great urban sprawl of Peru's capital city. It houses immigrants from other parts of Peru, all of whom are faced with a wide range of social, economic and cultural disadvantages every day. The housing is flimsy and vulnerable to the vagaries of the climate [chiefly a persistent drizzle] and all have extremely limited access to water and electricity.

The dwellings have 2 or 3 rooms to accommodate 10 people or so, and most Peruvians have large families. Wages are very low; 300 to 500 sols a month [£70 - £110] meaning that underage children have to work. Almost all work is seasonal or casual. Most children have only a primary education, so no 'technical' qualifications, and women are the main providers within the family.

Children with any disability in this environment face life-threatening challenges from the moment of their birth. The arrival of such a dependent child brings unimaginable economic challenges to a family where all children are expected to be able to work at some level from an early age. Those with profound and multiple disabilities are extremely vulnerable. Their families face many challenges, from society at large who are ignorant of the issues and the realities of having a child with disabilities; from health with many children on permanent medication; from difficulties of travel with the transport system unable to cater and sometimes oblivious of the needs. Their lives make the inclusive approach towards disabled children in this country, for all its short-comings, seem like an impossible dream.

Shalom [meaning peace and good relationships between people] which was established some 6 years ago provides the only care and support available to most disabled children and their families in this community, yet it is run not by the state, but by a dedicated team led by local Anglican Deacon Patricia Blanchard. I first visited it four years ago as part of a twinning journey from the Diocese of Worcester. What I saw there profoundly affected me, even though I have considerable experience of profoundly disabled children and adults as a former

Trustee of SCOPE, a current Trustee of BILD, and the mother of a young man with severe learning disabilities. Since I went there I have been supporting the fantastic work I saw, and encouraging others to do the same. In 2008 I returned to spend time with the mothers, children and therapists, so this article is based on first-hand experience.

Shalom's principle objectives area as follow:

- Integrate children within their families, and facilitate maximum independence
- Reduce levels of secondary handicap arising from mismanagement
- Educate mothers or primary carers in management of their children
- Provide pastoral and spiritual support
- Educate community on inclusion of disabled children in daily life

These objectives were established on the basis that if disabled children are seen as a 'separate' group, this provides a high risk to their survival and rehabilitation. It is crucial that work is done with parents for three great reasons: to educate them on disability issues; to encourage them to work with their children; and to ensure they play an active role in rehabilitation.

A 'Shalom' is desperately needed not just in Pamplona Alta but in all such poor parts of Peru. There is very limited state provision and assistance, and although there are some places for therapies they are not free; the Peruvian health service lacks many of the basic resources; specialized treatments of rehabilitation are not included in provision, and special school places are very limited and have to be paid for. Additionally specialist hospitals are located in other areas of the city and the transportation costs are high as the public transport is not suitable for those with disabilities so they have to take taxis to get there. In contrast in Pamplona Alta it is not uncommon to see mothers carrying their [early teenaged] children to Shalom on their backs in their shawls.

Shalom was born out of collaboration with a special

school in 2004, and by 2006 therapy sessions had begun, initially just physiotherapy. By 2010 the number of children on roll has risen to 60 with 43 receiving regular therapies each week, and the range of therapies has risen significantly to include occupational and language therapy. When the pre-school classes start this March a further 10 - 12 children will be coming each morning for pre school education and early stimulation.

The children range in age from under 1 year to 18 years, with most aged between 4 and 12 years. Almost 1/3 have a diagnosis of cerebral palsy while others have Down's Syndrome, West Syndrome, Microcephalia, Autism, motor and language deficiency or are classified purely as 'mentally deficient'. Cerebral palsy is quite prevalent in Peru; maternity services for those millions who live in shanty towns [as many as 8 million in Lima alone] are virtually non-existent and neo-natal care likewise unavailable.

The staff work incredibly hard. At present each morning a small group of the younger children receive pre school education and early stimulation and from 2pm till 7pm there is a rolling programme of therapies: speech, physical and occupational; with each child receiving attention according to their needs, once, twice or three times weekly. In the afternoons whilst the mothers and siblings are waiting, pastoral support is offered together with creative workshops and other practical activities to develop skills and share together. The therapists work long days, five days a week and earn about

£135 a week. They are funded through donations, by support from the Diocese of Peru and by a few pounds here and there from some of the mothers. Most however are unable to pay, and contribute by giving their time 'in kind' to prepare food, help with crafts or clean the property.

Current property is rented and very basic; it consists of just three rooms, with a kitchen, toilet and patio; the original location was in the garage next door, loaned by the mother of one of the first children to attend. However Shalom has just been able to acquire a much larger property, on two floors, close by. It was built as a school so has lots of classrooms and great facilities; there are some modifications to do, ramps etc., but that will be organised later. Funds were available as a loan to acquire, but Shalom now needs to raise the £18,700 to pay this back, plus the cost of the adaptations.

The impact that the therapists and pastoral workers have had on the children they work with has been phenomenal. Some children who had been spending all their days lying wrapped in shawls are now beginning to take their first steps; mothers are beginning to see what their children may achieve, rather than seeing no future; parents are finding support from each other. Their children are becoming precious again.

For more information on Shalom:

Revd. Patricia Blanchard
email: p.lanchar@anglicanperu.org

Summer Vol. 22 No. 2 Issue 66

- Sensory Experiences -

The copy date for all articles, information and news for the Summer 2010 issue is the
4th June 2010

Please send contributions to:
Di Foxwell
di@phonecoop.coop
Or
Chris Fuller
fuller.chris@hotmail.com

Summer Vol. 22 No. 3 Issue 67

- Lifelong Learning -

The copy date for all articles, information and news for the Winter 2010 issue is the
5th November 2010

Please send contributions to:
Beverley Dawkins
Beverley.Dawkins@mencap.org.uk

Articles can be long or short and they are welcomed from carers or professionals alike – we value YOUR experience and views. Please contact us if we can help you in any way. If you have any pictures or photos to include we would love to see them (providing we have permission).

Personnel Working in PMLD in Australia

Sheridan Forster

Centre for Learning Disability Health, Victoria, Australia

In Australia the term PMLD, or its international equivalent profound intellectual and multiple disability (PIMD) is not commonly used. The reasons vary from Australian state to state, with some states using only severe disability in education and other states avoiding categorising levels of intellectual disability. For this and other reasons, there is a very small collective profile for PMLD in Australia, no national bodies representing their interests, and fractured lobbying. Very limited information on demographics exist. We do know, however, that many children access early intervention, attend special or mainstream school, and, as adults, continue to live in the family home, group homes, or some in institutions, with a number of adults accessing day services. Despite this limited information, there are many individuals who are making a big difference in the lives of people with PMLD through inspiring practice and research. In this short paper I will mention some of the people in Australia who are contributing to the lives of people with PMLD, and have inspired me.

Starting from the western most state of Australia, Western Australia, is Helen Leonard and her team at the Telethon Institute. Helen has worked tirelessly for many years improving understanding of intellectual disability and rare syndromes. She set up the Australian Rett Syndrome Database. Helen's longitudinal work in Rett and Down's syndrome has improved understanding of aging and implications of the disabilities on day-to-day living. Helen has inspired many other researchers to become more involved in the lives of people with PMLD. One such researcher is Ellen Walker, who is looking at the experience of carers as their daughter with Rett syndrome transitions from late adolescence to adulthood. For more information about the Telethon Institute for child health research, go to www.ichr.uwa.edu.au.

In South Australia, Margaret Kyrkou, a general practitioner, has contributed significantly to the health of people with intellectual disability. Margaret's work on intranasal Midazolom for epilepsy has been particularly noteworthy. Her pragmatism has ensured that best science is transferred to everyday living, and she has been particularly instrumental in developing practice guidelines so that people with epilepsy and intellectual disability can receive the most effective treatment for their epilepsy when and where they need it. This pragmatic focus can also be seen in her contribution to the South Australian Department of Education and Children's Service program, Child Health and Education Support Services ([chess - www.chess.sa.edu.au](http://www.chess.sa.edu.au)). This program has supported many children with complex physical disabilities to be part of their schools with the support they need. Over the past five years of implementation their rigorous collection of data has also enabled a monitoring of the increasing number and complexity of health conditions of children.

In New South Wales for nearly two decades, Michael Arthur-Kelly and Phil Foreman have also been contributing nationally and internationally to understanding of the behaviour states of children with PMLD, and methods for enhancing alert states. With a focus on the classroom, they continue to explore means to support teachers and aides as key agents for enhancing alertness and communication, and examining the impact of setting more broadly. Most recently, with PhD student Deone Bennett and Project Co-ordinator Judy Neilands, they have been investigating the best ways to train teachers, from training sessions to in class mentoring.

Paul Pagliano, in Queensland, has been contributing research and practice development in the area of multi-sensory environments. Paul is not a stranger to the UK, and in the last few years he has taught, alongside Flo Longhorn and Richard Hirstwood, a course on understanding the theory of multisensory teaching and translating it into practice. In 2001, Paul published *Using a Multisensory Environment: A Practical Guide for Teachers*.

Living in Victoria, but travelling extensively across Australia and New Zealand, is Mark Barber. Mark Barber's name has become synonymous with Intensive Interaction in Australia. Mark provides practice leadership, training, and network building, and has also contributed to research on Intensive Interaction. Mark has been instrumental in clarifying necessary logistical matters of getting Intensive Interaction working in the school environment, such as paper work for compliance with education department policies and guides for enhancing the feedback and review processes of practitioners.

In Victoria, (and acknowledging my knowledge bias as this is where I live) we have been lucky to have two occupational therapists who have contributed significantly to practice with adults with PMLD. Mandy Williams, has contributed in the area of

enhancing the participation of adults with PMLD in their daily life. She is also the author of *Activities For Everyone: Arts & Craft*. Susan Fowler has been a leader in the area of multisensory environments publishing the very popular *Sensory Stimulation: Sensory-Focused Activities for People with Physical and Multiple Disabilities*. Together, Susan and Mandy produce the ECAPSS (Enhancing Communication and Participation Through Sensory Stimulation) newsletter, which goes out to over 70 members across Australia and can be found on the SCOPE Victoria website (www.scopevic.org.au).

In the area of communication, we are fortunate to have speech pathologists Hilary Johnson, Karen Bloomberg, Denise West, and Teresa Iacono. They have been instrumental in the area of assessment and development of strategies to enhance the communication of people with PMLD, through *The Triple C - Checklist of Communication Competencies* (revised edition - 2009) and the companion intervention resource, *InterAAction: Strategies for Intentional and Unintentional Communicators* (2004). Both of these resources are targeted to disability support workers. These authors have also inspired many others to expand understanding of people with PMLD, and Teresa Iacono, in particular, has led people to postgraduate studies to formalise this development. In addition to inspiring me, Teresa has inspired Jo Watson, who is exploring the impact of supported decision making on the lives of people with PMLD and those who

support them.

And finally there's me. I am nearing the end of my PhD journey, in which I have been looking at communication between adults with PMLD and disability support workers. In particular, I have been looking at how workers use affect attunement in their interactions. I've developed a small resource called the Hanging Out Program (HOP) to support interactions within service settings and encourage discussion around areas that may be operating as barriers to interaction (such as perspectives around touch) (www.cddh.monash.org/products-resources.html#hop). I've also been working to make links between researchers and practitioners in Australia, and to build the lobbying voice, to ensure that services don't forget about the special needs of people with PMLD. This is an area I hope to pursue further, particularly in ensuring that policy and practice guidelines are written in a way that can be meaningfully applicable to people with PMLD and not contribute to further isolation.

I believe that in Australia we will continually grow to be a strong force nationally and internationally to enhance good lives for people with PMLD.

Contact details

Sheridan Forster
Sheridan.Forster@med.monash.edu.au

INTERCONNECTIONS ELECTRONIC BULLETIN

**About Children and Young
People (0 - 25) with
Disabilities / SEN**

Note: You can receive the whole bulletin as an e-mail attachment if you request it by sending a message to p.limbrick@virgin.net. To view the listings www.icwhatsnew.com

**Peter Limbrick
Interconnections
E-Mail: p.limbrick@virgin.net
Web: www.icwhatsnew.com**

Have you sent your subscription for 2010 yet?

If you have forgotten to send it please do so as soon as possible so that your details can be updated on the mailing list ready for the Summer issue.

If your details have not changed you can just send a cheque with your name and address. No need for a form.

If your details have changed or you are a new subscriber, please use a form – you will find one at the end of this issue.

Links with Holy Trinity School, the Philippines

Dominic Carey
St Rose School, Stroud

My name is Dominic Carey and I am a student in the Post 16 unit at St. Rose's School in Stroud, Gloucestershire. This is a school for pupils with learning difficulties and disabilities. My school is part of the Global School Partnership. This finances links between schools in different parts of the World.

In March 2009 I was given the opportunity to go to visit one of the link schools, Holy Trinity in the Philippines, to experience what life is like there for pupils with learning difficulties. I was a bit apprehensive about going because of what I had been told about the living conditions and the poverty that is experienced by a lot of people in the Philippines. However, when I arrived, the students and staff of Holy Trinity were very welcoming.

I was very interested to see the differences between my school and theirs. Like St Rose's, it is a school that is run by Dominican Sisters. However, Holy Trinity is charity based and not funded by any education authority. The children and young adults are taught and looked after by the Sisters. In the Philippines children with learning difficulties are not necessarily entitled to a free education.

I quickly noticed how different life was compared to here. Apart from the obvious, the heat, the buildings and equipment the school had were minimal. Holy Trinity provides education and life skills to pupils with moderate learning difficulties. Pupils with profound learning difficulties do not go to school. They live at home with their parents or in orphanages. Whilst I was there, I had a chance to visit one of these orphanages. It was an emotional visit for me and made me realise how lucky the pupils with profound learning difficulties are in this country. Here, they follow a broadened, sensory curriculum. At St Rose's this includes physiotherapy, occupational therapy, speech and language therapy and massage. We have specialized teachers and learning support workers that support the pupils throughout the day. In the orphanage the staff carried out the physical care for the pupils but I saw no evidence of sensory.

The staff worked so hard! There were only two carers to bathe fourteen young people in a dormitory. They did everything; care, cooking, cleaning and feeding. The pupils were in wheelchairs, lying on the beds or lying on mattresses placed on the floor. The wheelchairs were shared and those who did not have them were carried by their peers. There were no activities in the evening; after a hot meal the young people were showered or bathed and got ready for bed. This

surprised me, as they started getting ready for bed at 5.30pm. The beds that they had were made of steel and the mattresses were about an inch thick. I tried lying on one and it was not very comfortable and some of the beds did not have sheets on them. Besides all this, the children smiled and seemed happy and were well cared for with loving support from the staff.

It made me feel very humble to see happy children that would otherwise not have homes and to see them with so little but still smiling. I realised how lucky I am and I came back with a different outlook on life.

Written by

Dominic Carey
(Supported by Wendy Newby)
Student at St Rose's School,
Stroud
Gloucestershire

Contact details

Wendy Newby
WenNewby@aol.com

The involvement of young people with learning disabilities in an international conference: moving beyond the factual to challenge our ideas on inclusion

Richard Rose
The University of Northampton

On the final morning of the 19th AFID Conference on Intellectual Disabilities held in Singapore towards the end of 2009, a plenary panel was assembled which included the academics from Taiwan, Japan, USA, Australia, Singapore, Malaysia and UK who had given key note presentations during the week. Each member of the panel was asked to give a brief summary of issues raised during the conference which they felt to be in need of further consideration and research and that might form a focus for future conferences. Each of the academics attempted to dissect some of the complexities, which had provided a focus for the weeks' deliberations. Their contributions covering such matters as increasing collaboration between schools and communities, strengthening interdisciplinary partnerships, developing improved assessment and diagnosis and increasing the skills of school and clinically based professionals were generally well received by a largely Asian audience anxious to address challenges in their own countries. However, their input assumed a secondary significance alongside the interventions of three panel members with a distinctly different perspective and experiences of the services under scrutiny. I will return to these three interventions later in this article, after a brief reflection on the general issue of participation.

The theme of the conference was "Towards Holistic Development of Persons with Intellectual Disability" and throughout the week young people with learning disabilities had been encouraged to participate in every aspect of the event. Earlier in the week sessions such as a report from the People First movement in Taiwan (Hung-Chung 2009) and a personal reflection of community living (Mei-Chi 2009) had provided a platform for people with intellectual disabilities to share their experiences and address a diverse audience which included teachers, parents and academics. These presentations provided far more than a series of insights into the lives of the individual presenters. They challenged the audience to consider the obstacles which have been created within societies, that prevent full access to appropriate services. They discussed the imbalance of power, which in many instances has resulted in young people being driven to the margins of the communities in which they live and added to their feelings of isolation. Each speaker presented innovative ideas with regards to overcoming some of these barriers and most significantly demonstrated the capacity which these presenters themselves had, to confront those exclusionary practices which have been put in place for the convenience of professionals and policy makers. Each individual spoke, sometimes with the assistance of interpreters, often using effective visual imagery to express their ideas, with conviction, but never with anything less than a rational and well presented argument. Their audiences were generally attentive and afforded each presenter the respect due to anyone who

delivers a session at an international conference. The applause at the end of each session was heartfelt and sincere. However, at the end of the first day I was left with a number of questions which have often troubled me at such events and for which there are probably no ready answers.

Whilst the participation of these contributors undoubtedly received a warm reception, and The Asian Federation on Intellectual Disabilities should be highly commended for their commitment to provide a platform for people whose voices have for too long been marginalised, I wondered to what extent they are able to influence change? I am not in any way suggesting that their participation within the conference was tokenistic, far from being in any way patronising this was probably the most inclusive conference I have ever been fortunate enough to attend. However, whilst the professionals attending these sessions were quite rightly impressed by the ability of the presenters to express their ideas and demonstrate the need for change, was their presence at the conference likely to make a difference? To what extent is it likely that those teachers, policy makers and academics, who it may be argued have far greater influence than the presenters themselves, will be committed to act on what they have heard during those sessions?

In recent years we have seen an increased commitment from some researchers to engage with people from marginalised groups when undertaking investigations which may impact upon their lives (Kenny *et.al* 2000; Moss *et.al* 2007; Lewis *et.al*

2008). The promotion of partnerships with people with learning disabilities in order to work with them in investigating aspects of their lives has commitment to both democratic principles and a recognition of the important insights that can be gained. However, as Lodge (2005) reminds us, if we are to move beyond the tokenistic we have to develop a commitment to engagement based upon mutual respect rather than seeing one part of such partnerships simply as a source of information:-

“Student voice has in some cases been understood to mean asking for the views of young people on comfort issues: lockers, food, uniform and toilets; but it can also mean developing a dialogue about what it means to learn in a school, for all members of the community”

Lodge (2005) p. 143.

The AFID conference had certainly enabled young people to have a platform, which moved the debate beyond the simplistic issues, which Lodge sees as often pervading discussions with people with learning disabilities. However, it was not until the plenary session that the majority of the conference participants were forced to sit up and take notice of what these young people had to say. Without suggesting in any way that the contributions of the key note academics at the plenary panel was anything less than erudite and well focused, it was not until three speakers with learning disabilities were given the opportunity to express themselves that the audience became fully engaged in debating the issues. The first of this speakers, a young man from Japan, speaking with the assistance of an interpreter, rather than giving us insights into his own experiences spoke critically of the failure of services provided by individuals such as those in the audience and the organisations we represented to involve him in decisions about his own life. Whilst welcoming the opportunity to contribute to the conference, and expressing gratitude to his Japanese colleagues who had enabled him to participate throughout the week he believed that such involvement continued to be exceptional in his life rather than the norm. His views were reinforced by the following two panel members. The first, a young lady from Bangladesh, supported by her mother demonstrated how, despite her lack of spoken communication skills, that she had been able to express her ideas through art. Her visual presentation to the audience provided a challenging view of how as a society we have often created barriers through our over elaboration of language. Finally a contribution from an Indian delegate informed us of how she had been enabled to make decisions for herself and take some control of her life. Whilst acknowledging the support which she still requires from adults, she expressed the view that she was now in control of her own life and received support when she asked for it rather than because

others assumed it was what she needed.

As each of the panel speakers completed their brief input, questions were asked from the floor. The chair of the panel suggested to the audience that this was possibly a unique opportunity to engage with keynote speakers who had travelled from around the globe to Singapore in order to share their latest research and ideas. To the great credit of the audience, whilst they recognised the contribution of the academics, they were far more eager to engage with the three presenters who could speak to them directly about their own experiences and the impact which each one of us has either directly or inadvertently had upon their lives. As each one fielded questions with an honesty and direction which is seldom heard at such sessions, the rest of the panel could only sit back in admiration and enjoy the interplay between panel members and audience.

At the end of the conference I was able to reflect on what had been learned. During the week I had heard presentations from researchers and teachers who have demonstrated a commitment to achieving a greater understanding of how we might better help young people to learn and take their rightful place in society. A series of practical workshops had shown how a variety of approaches to teaching through drama and music or structured interventions had enabled children and young people to access learning which had otherwise proven elusive. The commitment and determination of these presenters was unquestionable. However, it was the democratic inspiration of the conference committee to enabling interventions from young people to move beyond the factual and to challenge our own behaviours and commitment as professionals that will have impacted most on those of us in attendance. The conference convenors must be commended for not only providing a platform for people with learning disabilities, but more importantly for supporting them to move beyond the biographical account (which can still inform) to confront those exclusionary factors that continue to build obstacles to inclusion. As each of these speakers provided accounts of their own experiences they articulated their own ideas on how those professionals at the conference might work to either increase opportunities for inclusion and participation or add to the barriers which they perceived as standing in the way of progress. Far from simply talking about their own personal circumstances, they made demands for action and demonstrated how they understood that such intervention might bring changes to improve the lives of themselves and their peers. It is to be hoped that participants at this conference may make a similar commitment to involving young people in their own work to that demonstrated by the conference convenors.

The next AFID conference will be held in South

Korea in 2011 and it will be interesting to discover how the conference organisers build upon the expectations established in Singapore.

Contact details

Richard Rose
richard.rose@northampton.ac.uk

Have you sent your subscription for 2010 yet?

If you have forgotten to send it please do so as soon as possible so that your details can be updated on the mailing list ready for the Summer issue.

If your details have not changed you can just send a cheque with your name and address. No need for a form.

If your details have changed or you are a new subscriber, please use a form – you will find one at the end of this issue.

References

Hung-Chung, Chen. (2009) *People First Movement in Taiwan* Proceedings of the 19th AFID (The Asian Federation on Intellectual Disabilities) Conference. 22nd – 26th November. Singapore

Kenny, M., MvNeela, E., Shevlin, M., & Daly, T. (2000) *Hidden Voices: Young People with Disabilities Speak about their Second Level Schooling*. Report of Research Commissioned by the South West Regional Authority, Cork, Republic of Ireland.

Lewis, A., Parsons, S., Robertson, C., Feiler, A., Tarleton, B., Watson., Byers, R., Davies, J., Fergusson, A, & Marvin, C. (2008) Reference or advisory groups involving disabled people: reflections from three contrasting research projects. *British Journal of Special Education*. 35 (2) 78 – 84

Lodge, C. (2005) From hearing voices to engaging in dialogue: problematising student participation in school improvement. *Journal of Educational Change* 6 125 - 146

Mei-Chi, Chio (2009) (2009) *My Community Living* Proceedings of the 19th AFID (The Asian Federation on Intellectual Disabilities) Conference. 22nd – 26th November. Singapore

Moss, J., Deppeler, J., Astley, L, & Pattison, K. (2007) Student researchers in the middle. Using visual images to make sense of inclusive education. *Journal of Research in Special Educational Needs*. 7 (1) 46 - 54

Persons With Profound And Multiple Learning Disabilities In Japan

Shigeru Suemitsu
Professor of Kawasaki University of Medical-Welfare

The History of Care for PMLD in Japan

Medical care service and social welfare coverage for severely disabled child in Japan had emerged in the 1960's. At this time there were three institutions where a form of institutionalized PMLD care was being provided. However, this care was a volunteered service relying on people's good will and philanthropist's investment.

In 1961 parents of PMLD who were facing similar problems in caring for their children got together and formed the Parent's Association for Profound Multiple Learning Disability (PMLD). Their efforts prompted the government to explore a publicly funded solution to PMLD care services.

Until the 1960's early Medico-Social welfare administration in Japan was limited to children with mild and moderate intellectual disabilities and a small proportion of children with physical disabilities. Care for persons with severe intellectual and physical disabilities did not exist. Understanding and awareness in society was insufficient and people's attitudes were rather cruel and cool.

Children with either severe intellectual or physically disability, or with both disabilities were not covered by existing social welfare law at that time. Before 1960's, the socio - economical environment of Japan was still recovering from World War II. In such a social environment, parents of PMLD children had to struggle with the financial problems of caring for their children, who were often isolated from ordinary social life.

At this time society's reaction to PMLD children was harsh. In order to overcome such difficulties some parents felt their only choice was to terminate their child's life, or for the whole family to commit suicide. Such stories often appeared in the news paper or other mass media.

A well-known novelist, Mizukami, whose child had PMLD wrote an open letter to the Prime Minister Ikeda in a commercial journal and raised public awareness of the plight of these children and their need for society's help.

In this harsh and negative environment, the Parents' Association continued to press the government to help them and work in collaboration with volunteers and philanthropists who were funding the institutions providing welfare services for PMLD.

Members of Parliaments and bureaucrats at the time gave unusual reasons for denying assistance to PMLD children. For example they said that they could not spend tax on people who will never have a chance to pay it back by working in future. That was a fundamental argument used against PMLD persons. The movement, however, gradually gained momentum through the constant effort of supporters and activists.

Part of the reason this movement was effective and generated powerful compassion from society were that politician's wives were involved in this movement and their efforts, combined with pressure from mass media and normal members of society, brought about change.

Finally, aid for PMLD was included as part of the social welfare administration and hospital type institutions were funded by the government. These institutions were categorized as "Jyusho Sinshin Shogai Ji Shisetsu" which means Hospital for PMLD, and were clearly differentiated from existing facilities for mild and moderate disabilities. At that time, most parents considered it difficult to care for PMLD children only by the family, so in general, they wished for their children to be institutionalized at specialized hospital that combined welfare and hospital services.

As the government began to give support, Special Hospitals for PMLD run by non-governmental organizations increased. And they needed the Definition of PMLD as legal Term. For this we had used the Ohshima's scale for assessment of PMLD. Those client whose level of motor function are within a range of "keep sitting" and "Bed ridden", in association with intellectual level below IQ 35.

Integrated Care Model - Family and Hospital Staff Collaborate: Wheels on Both Sides of the Car

There was a strong desire among the parents of PMLD children to have all PMLD children living in

the institutions, as it was considered to be difficult to support them at home. Therefore, it was considered best to construct enough number of specialized institutions which provides medical care supported by social welfare law. 100% institutionalization was their aim at the time. Then Japan has constructed unique hospitals for PMLD which provide habilitation, chronic medical care and special education.

When the Parent's association "A Society for Protecting PMLD Persons" was formed, they established principles to govern their activities in a constitution. We strongly believe, this philosophy made their activity more effective, sustained and appealed to all members of society. It is particularly true in the socio-economic, and political environment at that period.

1. Never struggle with Person whose status is in a weak. They can not find the place to live under the environment of the struggle.
2. The parent should not bring their own political ideology to join this association.
3. This association must protect all the persons, covering even most weak persons.

Present Scope and Future Task Issues-Facing Hospitals and Institutions Servicing PMLD

Here, we would like to introduce the recent characteristics of PMLD institutions and the problems associated with them. For example, when the institutionalized care services of the special hospitals started in 1967 under the Child Social Welfare Law, it was considered that the life expectancy for PMLD would be around 15 to 16 years. From the variety and severity of conditions of the clients experts thought they would never live longer than 20 years old, and the number of the children with PMLD who live more than 20 years old of age must be very small. Therefore, the special hospitals should be governed under the Child Social Welfare Law.

However, as time went on, their life span has become much longer, and now the average age of those who live in the special hospitals is over 40 years old and persons over 18 years old comprise 90% of the total. Nowadays, the number of the special hospitals for persons with PMLD total 194, and the total number of the beds are 19,010. The number of people on the waiting list of living in the special hospitals for PMLD is 3000. About 300 children have not been discharged from NICU for more than one year because they need intensive medical care to live. However, the number of the babies staying at the NICU for less than one year is almost 6 times that number.

Currently the special hospitals for PMLD have two issues. The first one is the role for the children from NICU. Intensive medical care is necessary to them,

but that makes them being unable to go home directly. Therefore special hospitals for PMLD receive them from NICU and include intensive medical care. Then they start rehabilitation, counselling and training of the mothers to go home. Introduction to the community support team may be done before the children go home to help the mothers. Children from NICU essentially need much medical and nursing care. They have severe systemic condition requiring respiratory management, tube feeding and other medical and nursing care of high level of knowledge and skill.

The second issue is adults with severe motor disability and profound cognitive damage from variable reasons. This conditions means the patients can be classified as PMLD and this level of care is putting further strain on existing services. There is greater expectation to the special hospitals to provide continued and wide ranging care for persons with PMLD, as old as 60 or 70 years.

According to the score, persons with PMLD are classified into 3 types ; over 25 points are classified as PMLD requiring most intensive Medical Care, between 10 to 24 points are as PMLD requiring Semi-intensive Medical Care, and less than 10 point are as PMLD requiring ordinary medical care. The first photo (below) is of a person with PMLD requiring intensive medical care living in the special



hospital for PMLD.

It is estimated that approximately 25,000 persons with PMLD live at home. 6,000 of them use facilities for day care service tailored to PMLD needs. Others are going to special schools, with the remainder receiving their treatment at home and being cared for by family members. The second photo (on the following page) shows a child with PMLD requiring intensive medical care commuting to the special school. These persons living at home are increasing.

Age distribution of the persons using daycare center shows 2 groups, namely younger than 6 years old



and older than 18 years old. There are two types of day care center specialized for PMLD. Standard Type A has daily capacity for 15 persons, and Small Size Type B has daily capacity for 5. These facilities are being increased gradually. Nowadays there are 277 daycare centers throughout Japan and approximately 6,000 persons are registered.

By the amended law for school education in 1979, all of the disabled children are given the right of having an education. Nowadays, disabled children from 6 to 15 years of age, either go to special schools, or have visiting teacher from those schools. As a result, over 99.97 % of disabled children, at present, are given a school education. To the family who care for children with PMLD at home, short stay care is very important supporting system. Seeing the distribution of reason for using short stay service, the most one is "refreshment of mothers" followed by "disease of family member", "rehabilitation for daily living" and "delivery by mother". Total man-day number is more than 100,000 in 2008. Because of the increase in PIMD living at home there has also been a greater need for nursing, rehabilitation and care workers to visit homes and provide care services.

Advocacy for the Dignity of PMLD client

Nowadays, advocacy for the dignity of PMLD clients is widely accepted and society is sympathetic to their needs. However, this was not always the case. It is often overlooked that this social situation can be maintained by both society and law. And their dignity as fully humans can be promoted by the enthusiastic and seamless efforts of people involved in their care and activists who supported their cause.

Here, I would like to introduce some examples concerning these issues.

Mr. H. Kitaura is the only one of the first and most committed activists for the rights of PMLD. He contracted encephalitis after a small pox vaccination

given at the age of 7 months. Since then, he is on the bed all the time and is unable to speak. He was institutionalized at the age of 24. He was able to progress and he could turn over by 40 years old, and then he could hold a brush by 48.

Photo 3 (right) is an example of the work he produces. This is a wonderful example of such through care for persons with PMLD can develop their abilities even though they are 40's.



Mr. Kozuka received brain damage at birth, which has led severe motor and intellectual disability. He, however, lived his entire life with a full of love from his family member, parents, grand parents and elder brother. He has lived in a special hospital for PMLD since 5 years of age. Again he could live with full of love from staffs and school teachers in the hospital. He passed away at the age of 23. Afterward Parents wrote a book using all the records about him and memory remained in their heart.

One day pupils from an elementary school visited the day care centre for PMLD (see photo 4 below). They were very impressed by observing the PMLD clients trying to do something with their limited ability in a rehabilitation session. One pupil wrote a letter after going back to school. The letter said, 'I feel very sad whenever I see the news of murder or suicide. However seeing their spirit to live under such hardships taught me the importance of life. If I may struggle with something in the future, I will try to



overcome it by thinking how they live.'

Future scope of institutions providing PMLD Care

Special hospitals for PMLD now fulfil a diversity of roles in providing PMLD Care.

Major examples are as follows:

1. Among those in specialized hospitals, if the degree of disability is mild and the client agrees, they are encouraged to move from there into their community or other kinds of facilities. They are supported financially in order to achieve this because it is considered that it will help for “self advocacy.”
2. For clients staying in NICU whose parents wish to move into the special hospital, we should try hard to receive them.
3. Aging and increase of medical care may need more number of caregivers and nurses.
4. There is an increasing tendency to rely on the day care centre or short stay service governed by the special hospitals dedicated to PMLD care.

In virtue of the “Service and support for person with disability act” passed in 2006, the number of clients who utilize the service for short stay, became almost 10 times than before. However, if the client requires the most intensive or semi-intensive medical care, community service is not enough to provide secure and proper care.

Contact details

Shigeru Suemitsu
suemitsu@asahigawasou.or.jp

The multifaceted condition and collective competence

Peter Limbrick
Independent consultant

In promoting the idea of the 'multifaceted condition' in this essay, I am going to argue against the traditional idea that an infant can have 'multiple disabilities' that must be treated by 'multiple practitioners'. The phenomena 'pantry' and 'pastry' might help me get my point across. As words they differ in only one letter but, as elements in the kitchen, are very different in how they are composed. A pantry might store, amongst other things, sugar, fat and flour. They do not interact with each other on the shelf, you can remove any of them at will, and, if you go on a health spree, you can replace the lard with vegetable fat, the white sugar with brown and the white flour with wholemeal. They are three elements among the multiple items in the pantry.

Not so with pastry. Now the fat, flour and sugar have merged together in the mixing process and have interacted with each other in the oven. They are no longer separate entities and cannot be taken out should you change your mind about the sort of flour or sugar or fat you used. In the cooking process they have interacted with each other to produce a new entity – pastry, that has taste, texture and nutritional value that the separate ingredients did not. It is no longer meaningful to look for the flour in the pastry or even to think in terms of the flour from the pantry being inside the pastry. It is not. It has become part of something else and is no longer flour.

Before I get to the 'pastry' of the multifaceted condition, it needs to be acknowledged that a grown man or woman can have multiple disabilities just as a pantry shelf can have multiple food items. Suppose I emerge from a car accident with a damaged eye, burns, a ruptured stomach and shattered knees. I would not object to being described as having multiple disabilities and I would expect multiple medics to tend to my needs. I would not expect that the damage to my retina would have much impact on my knees and I would not demand that the burns specialist goes into conference with the gastric surgeon. I would be content for these multiple practitioners to get on with their tasks more or less separately over the coming months and years on my multiple problems.

After my imagined car accident my injuries and disabilities remain more or less separate from each other like groceries in the pantry because I completed my child development processes some time ago. But what about the infant who is deeply and perpetually involved in the process of development and learning, and in establishing the necessary new neurological connections and pathways that allow new behaviours now and yet more new learning tomorrow? Though the relevant specialists and parents might identify such separate entities as cerebral palsy, visual impairment, hearing

impairment, autism, learning difficulty, etc, we should consider these items to be much more like ingredients in pastry in an oven than like groceries on a pantry shelf.

My argument is an infant's separate conditions become cooked together into a new and unique entity in the development and learning process at the neurological level. Imagine an infant who has dual diagnoses of cerebral palsy and significant visual impairment. Her learning will be in the context of the two conditions interacting with each other, and the resulting neurological structures will be the product of those interactions. Hand/eye co-ordination, for example, will develop very differently in a child with this dual diagnosis to a child with just one of them. While a baby with visual impairment might reach for a bauble – with increasing accuracy and reliability as neurological connections develop in response to the behaviour, the child who also has cerebral palsy has to reach out using body posture and arm and hand movement that are making her task more difficult and success harder to achieve.

We can also look at the bauble-reaching task from the point of view of the physical impairment. The child, who already has a much harder task than a typically developing infant as she attempts to get her hand to the bauble, has to struggle with imperfect vision that makes it harder to locate the bauble in space.

So it is my contention that the emerging neurological pathways for hand/eye co-ordination in this infant are the product of both conditions (and of course of such other factors as personality, motivation, attention, etc) and that the product is like pastry in that the separate ingredients can no longer be found. They have inter-acted with each other – or fused together – and brought into being a new entity which we could label 'blind cerebral palsy' or 'cerebral palsy blindness'.

We can envisage another dual disability to help promote the idea of the multifaceted condition in preference to that of multiple disability. This toddler, who has significant hearing impairment and is on the autism spectrum, is establishing new neurological pathways and connections in response to, amongst other influences, his encounters with other people. In these interactions and relationships he has to endure, enjoy, accommodate to and celebrate much the same things that other children of his age on the spectrum are also subject to – but he has to manage without hearing. The corollary is that while he faces the challenge of learning an alternative non-hearing communication system, the outcome, in both behavioural and neurological terms, will be significantly altered by his autistic features. In his multifaceted condition of ‘deaf autism’ or ‘autistic deafness’, there is no pure deafness or pure autism to be found – there is only the fuse of the two.

We could continue the theme and look at children with three or four or more labels – and this would certainly help emphasise the uniqueness of each child with a multifaceted condition, but the space in this essay might be better used to consider how the concept of the multifaceted condition could impact on early childhood intervention, or early support, for these children and their families.

In my experience in the UK, our most common approach borrows much more from the pantry than the pastry. We model our interventions on the treatment of the car accident victim envisaged above as though, in the developing child, the various conditions and disabilities are somehow not interacting with each other in the child’s development and learning – as though the physiotherapist can promote reaching without considering the visual issues, and as though the hearing-impairment teacher can promote communication without considering the autistic features. Our knee-jerk response to the child and family’s need, perhaps bowing to traditional thinking, perhaps bowing to parental pressure, perhaps bowing to managerial demands, is to treat multiple disability with multiple practitioners and separate programmes.

There is a general and growing awareness about all young children that we should treat each one as a whole child – but if this is seeping into the training of early interventionist teachers, therapists and play workers, it is doing so remarkably slowly. With our fragmented health and education interventions it can appear that we expect the infant to do posture and motor work on Mondays, language and communication on Tuesdays, play and hand/eye co-ordination on Wednesdays, seeing and hearing on Thursdays, cognition on Fridays and then learning about bathing, dressing and mealtimes over the weekend. We know that typically-developing infants

would demolish such an ill-advised approach in minutes but we expect disabled children, including those with a learning disability, to learn in self-contained segments and then (as their homework perhaps) to try to fit it all together into something which helps them function in the world as whole beings.

Following and developing a whole-child approach to development and learning, we should explore in early childhood intervention, or early support, how to meet each multifaceted condition with a multifaceted intervention system. This means acknowledging the inevitable fusion of conditions in new neural pathways and anticipating and promoting the process by fusing together our interventions.

When I talk on this subject, this is the point where some practitioners and parents anticipate my preferred approach to be either the Peto Conductor or some dumbed-down Jack-of-all-trades. Though I am a great admirer of Conductive Education I do not see UK services going in that direction. I dismiss the Jack-of-all-trades because infants with multifaceted conditions have a right to support from all the highly trained expertise we can focus on them – and this includes specialist practitioners trained in separate disciplines. I want ever more expertise available to these children and their families.

The challenge these children bring to us (and we should thank them for the wonderful development and learning opportunity) is to find ways to put our separate strands of expertise and experience together *before* they are delivered to the child and parent. This requires more skills and more professionalism than do separate programmes and it requires all of us to find ways of collaborating with each other – even in the absence of effective training in multi-disciplinary teamwork. The forum for this can be the small collaborative TAC (Team Around the Child) which comprises just two or three key practitioners and parent, and the process they can employ is collective competence.

Achieving collective competence means, taking as an example the infant with blind cerebral palsy, mother, physiotherapist and visual impairment teacher coming together in regular TAC meetings to share observations, ideas and aspirations, to learn from each other and to find creative whole-child approaches to such development and learning tasks as moving around the home, playing with toys, communication and socialisation, managing clothes, etc. The reader will recognise than none of these activities are the province of any single practitioner. It can be helpful, when planning development and learning strategies, to move away from thinking about which practitioner a child might need to which interventions the child might need – to move from, ‘The child needs to see a Physiotherapist.’ to ‘The

child needs help now in playing with toys on the floor.' This can help us keep our thinking open and multifaceted and to remember that any solution is likely to come from collective competence.

I would like to finish by looking at the same issue from another angle. When we apply the old principle of sending in a new practitioner for each need that arises, do we ever ask ourselves if this vulnerable infant is socially, emotionally and psychologically ready for a new relationship with yet another adult, to be manipulated by yet another pair of hands? If the infant is still a babe in arms, if there is a sensory deficit, if the mother and child have not yet bonded with each other, if the child has a learning difficulty, then the answer might well be 'No'. In which case the multiple practitioners might be doing more harm than good.

These infants with their multifaceted conditions invite us politely to be more creative and to find solutions that are more child-friendly for delivering our skills and experience to mother and child. TAC's multifaceted collective competence achieves that and also provides the parent with a small and trusted team for helping her think through all the difficult decisions and dilemmas that arise in families.

Contact details

Peter Limbrick
p.limbrick@virgin.net

Future Focus: Sensory Experiences

Guest Editors
Di Foxwell and Chris Fuller

Our next issue, due out in the summer, is set around the theme of sensory experiences and as the guest editors we are excited and stimulated by the contributions our writers have sent us so far.

For many of us the two words “sensory experiences” will bring to mind the experiences that enhance our everyday lives. They may conjure up beautiful relaxing scenes..... floating music, a warm bath, lots of bubbles, perfumed candles by the bath taps and a glass of chilled white wine. Complete this with an open window, sunshine and the sound of birds singing. Mmmm heaven, or is this sensory overload!

Most of us who are able to read this journal have the ability to create our own sensory experiences and to access them with ease. Yet for many of the children and adults we care for, work or play with, making contact with their immediate environment for day to day sensory experiences, will need our help and sensitive support.

True we can usually provide a warm bath, bubbles and candles but to enable young people and adults with PMLD to enjoy and fully participate in their own little piece of heaven through music, dance, theatre and stories, often presents more of a challenge.

Through the development of various therapies and techniques we are able to help people with complex needs experience more of the world around them and our next issue has many excellent contributors whose contributions are quite diverse in their writing styles and content.

We have articles not only about enhancing/decreasing sensory experiences, but also audits of sensory materials available on the market. Our writers range from first time writers to some of the most experienced in the field.

All of this promises to be a great edition and if you are busy doing fantastic things, have enabled someone to have a great holiday or day out or are simply providing everyday sensory experiences you would like to share with our readers and see included in this edition, please contact either of the guest editors before the end of May.

The guest editors for the next edition are Di Foxwell and Chris Fuller

Send your contributions to Di Foxwell: di@phoncoop.coop or Chris Fuller: fuller.chris@hotmail.com



PMLD Network Email Forum A Digest of Discussions November 2009 to March 2010

The PMLD Network forum is an open email discussion group which focuses on issues relating to PMLD. Here is a summary of the key themes that have come up on the forum over the last few months:

1. **Accessing therapies within day services for people with PMLD**

Someone wanted to find out what is happening in different areas regarding the provision of physiotherapy, occupational therapy and speech and language therapy for people with PMLD. They wondered if there are any examples of these services being joint funded by Health and Social care within day services and if so how this is organised and managed.

Someone said delivery of therapies needs to be looked at for children with PMLD as well as adults with PMLD. They said that in their borough services for children are stretched between disabled and non-disabled children, so disabled children don't get the level of input they need.

Someone from Postural Care Skills said they are really interested in supporting families and those supporting people with complex healthcare needs to self manage therapeutic intervention - mainly in relation to protection of body shape and postural care. They said that the 'It's My Life' care pathway may be of interest to people: www.choiceforum.org/docs/mylifev2.pdf.

Someone said that in their local area it has been the practice for several years for qualified physiotherapists to 'manage' their clients and monitor progress while the therapy is actually delivered by physiotherapy assistants or learning support assistants.

Someone said that where there has been a shortage of therapists within the local health service and a danger of a therapy specified within a statement of SEN not being delivered, the children and young people's service or even the special school itself has sometimes employed its own therapists.

Someone said that they are not sure what arrangements can be made (to access therapies) once their son/daughter leave secondary education. 'I feel we need to engage in huge amounts of

investigation and forging new relationships with key people in Adult care services and health. It seems rather difficult to discover what does go on. People are very vague saying "it is very different in adult services" (they seem to imply that 'different' means 'hard to find' or even 'non-existent'). I almost get the feeling that there will be no continuity of care unless my husband and I go out and set it up! Is this a common situation?'

Someone else said that when in special school there's a regular service provided by OTs which is imperative for those with chronic conditions but after transition this provision has disappeared. A reason always given is 'there is a shortage of therapists' - but this has never been addressed. They said that to go from having therapy to none is very traumatic and needs to be addressed.

2. **Arts organisation that promotes collaborative work between artists both with and without learning disabilities**

Someone who is joining the board of an arts organisation that promotes collaborative work between artists both with and without learning disabilities was interested in contacting other similar organisations nationwide.

Suggestions included:

- www.first-movement.org.uk
- The Rockets: www.rocketartists.co.uk/ - who work mainly alongside students
- Into Art: www.intoart.org.uk/studio/index.html
- Project artworks: www.projectartworks.org/
- Carousel: www.carousel.org.uk/
- A couple of people said they had found the Pallant Gallery 'Outside In' exhibition inspiring. More information at: www.culture24.org.uk/art/art70931.
- Someone also mentioned the Partners in Art scheme at Pallant Gallery which supports people who have difficulties in accessing the arts. On the scheme they are placed in partnership with a trained volunteer to share and develop their art practice. There is also a DVD about this scheme. For more information: info@pallant.org.uk

3. Hospital finds it very difficult to assess plight and is rather fearful to make suggestions

Someone said that their adult daughter has PMLD and has virtually no capacity to express a reason or source for any distress, even to those who know her very well. They said they are currently struggling with very severe digestive issues – which they think may be developing as a result of the need for multiple epilepsy medications over many years. They said that their local hospital finds it very difficult to assess her plight and is rather fearful to make suggestions. They asked if there are any families on the network who have come across a hospital with staff who are comfortable at working with such a patient.

This posting prompted a lot of responses on the forum.

There were some suggestions of organisations which might be able to offer advice:

- National Centre for Young People with Epilepsy: www.ncype.org.uk
- David Lewis Centre: www.davidlewis.org.uk
- St Margaret's School in Tadworth, run by the Childrens Trust www.thechildrenstrust.org.uk
- Chailey Heritage School which is attached to Chailey Heritage Clinical services: www.chs.org.uk
- Patients on Intravenous and Nasogastric Therapy (PINNT) which is run by patients and carers but links in and gives feedback from its members to NICE and other professional organisations: www.patient.co.uk/support/PINNT.htm

Many people said that the person with PMLD who they support had faced similar issues in hospital:

- My team and I faced a similar situation last year with one of our service users. We worked tirelessly monitoring and recording all changes. Including changes of skin colour, Eye movement and grip of the hand. After a long haul struggle and perseverance, along with the help of the health liaison nurse, we managed to convince the doctors to listen to us and diagnose the condition and start treatment.'
- 'My adult daughter seems to share most of the issues you describe in your posting. I have yet to find any hospital, anywhere, that is truly geared to providing adequate support for our daughter.'
- 'I feel the original parent has opened up a very common link – hospitals just can't cope with the complex health and care needs of our sons and

daughters no matter how much they say they can. Unless we stay with my daughter 24/7 on the ward then I would be fearful that she would not survive the hospital stay.'

Some people shared information about documents they have produced or are using when someone with PMLD goes into hospital. However, many said these documents are not always read by staff:

- Someone said that their daughter has an Admission to Hospital Information pack devised by the learning disability team, the parent, and supported by the local partnership NHS and Teaching Care Trust. This has lots of information including best interest/ capacity and consent issues, communication and awareness, whether or not she can be left unobserved and her method of expressing pain. 'Most importantly there is a picture of her when she is well so that they can see she is indeed a sentient human being and have something to aim for instead of dismissing and ignoring her.'
- 'Oxfordshire have an "All About Me" book which is purple and similar to the red book for babies. But it's not ideal - it doesn't take into consideration the fact that medications can change monthly, that more than one hospital may be involved, that policies for schools and for respite services and hospice and social services carers may differ and therefore treatment and care plans may differ.'
- 'In our area we now also have a Hospital Passport in place, but, thank goodness I've not had the opportunity of seeing if this works.'
- When accompanying my daughter to hospital for whatever reason, I go armed with a document I keep regularly updated, but the problem is, Doctors, Specialists etc do not read it or don't take any notice of it.'
- 'We have a patient profile which is just one sheet of A4 which is a brief guide for all essential information, which is a quick read for busy staff (not that this is always read) and we have an alert box on the front to indicate the person may have extra needs. I am in favour of a document that covers all sorts of situations and experiences, but have found few staff have time to read and take on board all this information.'
- 'We have found that the Traffic Light document - when being admitted to hospital - has been invaluable. Yes, busy nursing staff may have to be prompted to read it and doctors and consultants but knowing how to communicate with a person, support what health needs are known and who is important to the person, can save a life at worse and at best improve the care of the person.'

- Someone said they have a very detailed care plan for their daughter but do not have a more concise document that would go with her on an emergency admission. Having heard on the forum that other parents have done this – they think it is a very good idea and asked if anyone would be happy to share a copy of what they have put together.
- ‘My experience is that with greater expectations on all healthcare workers, along with inadequate staffing levels, the dedicated staff teams have to rely on carers and families to support the patient in terms of feeding etc. All the staff I work with are dedicated to providing the best service they can, with the resources available.’
- The person who originally posted the query said they do have a variety of documents prepared – both brief summaries and more detailed histories depending on the situation of the time. However they said that their previous experiences at the hospital have unfortunately demonstrated that all of this is ‘of absolutely no use at all in preventing needless distress, pain and stress to my daughter.’

Other suggestions about how to address issues being experienced

- ‘is important that as carers we do raise these issues with providers otherwise the service being provided will continue to be unacceptable.’
- ‘I don’t think it is acceptable for doctors, nurses or other health professionals to say that they are ‘too busy’ to look at a health passport. Failure to do so would, I think, be likely to render them in breach of their professional codes of conduct and they and their managers would be at risk of being seen as failing to make the ‘reasonable adjustment’ to their practice required by the law. By all means make sure the passport is concise, well presented and up-to-date. Offering to take people through the key points would also be helpful, no doubt. But if faced with refusal to take notice then feeding this back to the Learning Disability Partnership Board so it can take it up at a senior level seems to me an appropriate action.’
- Someone else asked if people had tired requesting an Equality Impact Assessment (EIA) from the Hospital Trust (re: the issue that a hospital does not have adequate ways of communicating with patients with complex needs and their families). They said this is an underused and effective piece of law which comes from the Disability Equality Duty (DED) 2006, affecting all public bodies. The hospital would have to consult with people affected, and publish its conclusion and action plan. ‘It brings discussion away from a busy ward culture and gets focus and scrutiny in a very public way’.

- ‘My suggestion is that we co-produce a conference and make a film about this specific issue. There are many communication passports, traffic light systems, health action plans and creations by families that are desperate to be heard so that their loved one is safe. The design of such tools is not the issue. The issue is the culture and practice of no time. If anyone wants to get in touch to share their experiences and think about how to change this culture, contact www.frameworks4change.co.uk

4. Re: Circles of support also being paid support staff

Someone said they were in the process of developing an ethics application for research they are doing and the ethics committee is concerned about paid support staff also being members of someone’s circle of support. She has explained that this scenario is very common because people with learning disabilities don’t have a lot of supporters to choose from. She wondered if anyone has got anything written in the way of guidance to assist support staff in this situation. She wants to make the point that for some people there is actually no getting around the fact that paid support staff may also have a role of being really important people in the person’s life and therefore should be part of their circle of support.

Responses included:

- A number of people said that they don’t think it matters whether the people in someone’s circle are paid or unpaid:
- ‘It takes time to get to know my daughter, takes time to learn to read her communication, time to understand how to move her and to work out what she does and does not like. Perhaps I’m being simplistic, but I’d want one of those paid support staff at least to be considered part of the circle of support around my child; who else is going to know her like they do?’
- What is important is that there is someone there, and that there are sufficient people who are involved to help the person access a wide range of things that they otherwise couldn’t. And the more they know about the person, the better.’
- Someone else said that they personally don’t think paid staff should be on someone’s circle (although possibly in an adviser’s role because they know so much information about the person). They said: ‘I believe if you start a circle with paid staff you are back in service land again, even if it’s direct payment and they are personal assistances.’
- ‘Embrace Wigan and Leigh’ said that in their area they have started to develop sustainable circles of

support and they now have 9 circles. Some of these are for people with no-one else in their lives apart from paid staff. However, they have managed to set up circles without having to use paid support. They said 'it hasn't been easy but we managed it, and the circles are working very well.' For more information contact: info@embracewiganandleigh.org.uk

- Someone said they think the research sounds interesting and hopes that when finished it will be available for PMLD network members to obtain.
- On a related note someone said they are collecting data for a research project: 'Friendship Matters?' - looking at the significance of friendship in the lives of adults with profound and multiple learning disabilities: They said they would be interested in hearing from people who either identify themselves as a friend of an adult with PMLD or consider friendship to be an element within their relationship with an adult with PMLD. For more information about the study contact rmp49@medschl.cam.ac.uk

5. **Joint plans for people with a learning disability and complex needs**

A clinical nurse specialist in children with learning disability and complex needs said they were interested to hear from anyone involved in using and developing care plans for children in residential and school settings. Someone else also said they would be interested in hearing from any therapists who have developed joint plans for people with a learning disability and complex needs - they said they have recently brought physiotherapy, OT and speech and language therapy together to look at joint outcomes.

Responses included:

- Someone who is a director for Stride training and also an Assistant Head of a Special School in Brent said she is working with an OT on a type of planning facility which will enable them to work on the holistic needs of the child/young person under the umbrella of facilitating their 'wellbeing'. They said it is very current thinking and is more descriptive than separating into care, education, therapy. She asked if anyone was interested. She can be contacted at www.stridetraining.co.uk
- Someone said it may be useful to look at 'My Life Plan' - an interactive CD Rom which enables a whole picture to be built up and updated, with the student at the centre throughout. They said you can see a short film about how it works on the 'Watch us in action' pages at www.frameworks4change.co.uk
- Someone said their team in Leeds have produced policy and guidelines around meeting the needs of pupils with complex and multiple learning needs using Personalised Learning Plans,

produced by a multi professional team including the parents, which they are happy to share:

- Curriculum policy for pupils with complex learning needs www.choiceforum.org/docs/curr.doc
- Curriculum guidelines for pupils with complex learning needs www.choiceforum.org/docs/curr.doc (they would ask that anyone using the materials acknowledges the team).
- The team also offers a training package. For details of this see: www.choiceforum.org/docs/tra.doc Their team can be contacted at cmlnteam09@googlemail.com
- Someone else suggested looking at 'Hello this is me' - published by Jessica Kingsley.

To take part in discussions please join the PMLD Network Forum at http://www.pmldnetwork.org/about_us/join.htm

Visit the PMLD Network website at www.pmldnetwork.org

NEWS

Supporting people with profound and multiple learning disabilities to be involved in their communities

People who have profound and multiple learning disabilities have a better lifestyle when they have opportunities in their communities and develop relationships with people other than paid staff.

Being part of your local community does not just mean going out and about to local places - it also means having connections to people and being appreciated for who you are and what you bring.

Changing Places campaign petitions decision makers

Member organisations of the Changing Places Consortium have petitioned decision makers in Westminster and Holyrood to change building regulations to make Changing Places toilets compulsory in big public places.



In London in December, Craig Kelly ('Strictly Come Dancing') with the help of local campaigners, including Rosemary and Hollie McLean (pictured), delivered a giant toilet roll representing the over 18,000 people who signed the petition, to the building regulations minister, Lord McKenzie.

Lord McKenzie commented: "I was very happy to meet the delegation today to hear about their campaign on this important issue. The government will listen carefully to their views when considering what future changes we can make to the building regulations."

In Edinburgh, Pamis representing the Changing Places Consortium is now in discussions with the Scottish Parliament following their petition to Holyrood.

Find out more about the Changing Places campaign and how you can get involved: www.changing-places.org

Families still waiting for a break

Despite increased funding for short breaks, some families are worse off than in 2008.

New research from Mencap has revealed that despite increased levels of government funding for short breaks, some families with severely disabled children are actually receiving a reduced level of service compared with 2008.

As part of Mencap's 'Breaking Point' campaign, 'Still waiting for a break' reveals that a £370 million package provided to local councils in 2008 - along with another £270 million for primary care trusts - is failing to meet the needs of many families of children with profound and multiple learning disabilities (PMLD).

Mencap worked with 40 families living in nine areas in England to find out whether those who most need short breaks are now getting them, and whether families of PMLD children are still being allowed to reach breaking point.

It found that 3 in 10 families are receiving no short breaks or a reduced level of service compared with 2008, and only 1 in 4 of the families saw an increase in their short breaks in 2009.

"The conclusion of our work is that families of children with PMLD are still not a priority for local councils and primary care trusts," says Lesley Campbell, Mencap's national children's officer. "Children with PMLD provide the litmus test for the new funding for short breaks. If it is not reaching the families with the most complex needs then this investment is failing to reach its target."

Launched in 2003, the 'Breaking Point' campaign calls for a minimum level of short breaks for families caring for children and adults with severe and profound learning disabilities.

"It is of great concern that six years on so many families of children with PMLD still feel close to breaking point. The government funding that was designed to provide a 'step change' in short breaks is not having the positive impact that was envisaged for these families," says Lesley Campbell.

Download the 'Still waiting for a break' report: www.mencap.org.uk/document.asp?id=12815

Find out more about Mencap's Breaking Point campaign: www.mencap.org.uk/case.asp?id=542

Launch of 'Raising our sights' – a report on services for adults with profound and multiple learning disabilities

'Raising our sights', a report on services for people with PMLD in England, was launched on 19 March by the Department of Health.

The report was commissioned by the Department of Health as part of the 'Valuing People Now' delivery plan, and was written by Professor Jim Mansell of the Tizard Centre at the University of Kent. Speaking at the launch, he said that good services are individualised and person-centred. "The government's personalisation agenda is the right one."

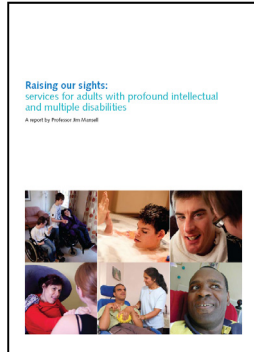
While good practice does exist, Professor Mansell highlighted prejudice, discrimination and low expectations as obstacles to its wider implementation. He also said that a lack of resources may restrict the speed of change, but that this shouldn't affect its direction.

The report makes 33 recommendations across areas such as health, wheelchairs, assistive technology and day activities. As well as emphasising personalisation, it says that good services should treat the family members of the disabled person as experts, focus on the quality of staff relationships with the person and sustain the package of care. A film accompanies the report, using the experiences of four people with PMLD (including James Cooper, pictured) and their families to show how good services can work in practice.

Bruce Calderwood, director of mental health and learning disabilities for the Department of Health, welcomed the report. He said that the government would formally respond to it in due course, but "the philosophy and overall approach is one we echo."

Beverley Dawkins, chair of the PMLD Network and national officer for PMLD at Mencap, said: "We welcome this insightful report and urge all commissioners to follow its recommendations. People with PMLD and their families should not have to fight to get the support and services they need, it should be their right."

Read the report: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114346



Mencap's Valuing People Now fact sheets & poll

On 19 January 2009 the Department of Health published its three year strategy for learning disability services in England. For 'Valuing People Now' to work, local Learning Disability Partnership Boards across the country need to start springing into action. For this to happen, we need people to be our eyes and ears on the ground, to ask the right questions, and to put pressure on local boards to ensure things are being done effectively.

To help this process, Mencap have developed some new fact sheets on Valuing People Now. These are available at www.mencap.org.uk/valuingpeoplenow.

The factsheets will help you approach your local Learning Disability Partnership Board on the key issues relating to 'Valuing People Now'.

Mencap also would like to hear your views on how well you think your local Learning Disability Partnership Board have been getting on with implementing the Valuing People Now strategy locally. You can do this by filling in our very short poll on the Mencap website: <http://www.mencap.org.uk/page.asp?id=13830>

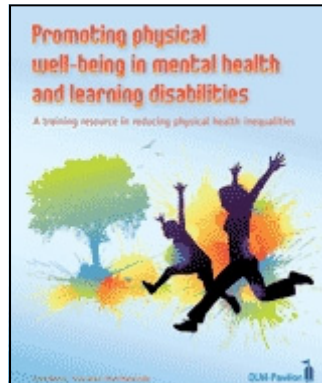
RESOURCES

Promoting Physical Well-being in Mental Health and Learning Disabilities

A training resource in reducing physical health inequalities

Anne Ellison, Tony Dwyer, Mark Hardcastle

Do you want to organise and run a healthy living group? All it takes is a little information, good sense, and the ability and support to and help your service users to make a few healthy changes to their lifestyles.



This pack is a facilitator's resource, which will enable you to set up and run a healthy living group that will be fun and interactive for community groups and individuals, including adults with specific conditions such as mental health illnesses and learning difficulties.

Price: £95.00

ISBN: 978 1 84196 254 2

Publisher: Pavilion Press

A Life Better Spent?

This is a new DVD about personal budgets and making a change in your life made by and for people with learning difficulties.

Contact:

Sapna Sharma

Tel: 020 772 954 36

Email: sapna.sharma@viauk.org

Training Personal Assistants: Help Your PA to Support You Better

About the workbook

Kerrie Ford and Lisa Ponting were researchers on the project, which was funded by the Big Lottery at the West of England Centre for Inclusive Living. They worked in partnership with Norah Fry Research Centre.



Workbook content

This book has four parts:

- Part one tells you about good support
- Part two has ideas about how to train your PA
- Part three has five photo stories that you can read and use to get ideas
- Part four has notes for PAs, managers and trainers, including background policy

DVD content

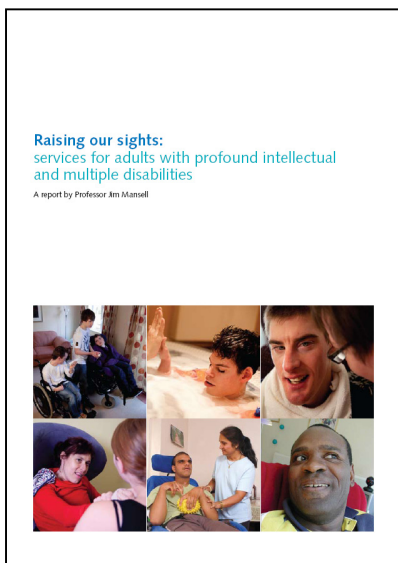
The DVD shows real life clips that were made during the research project. It also shows some scenes from the past, which show bad support. You can watch the clips and talk about them, to think about good and bad support.

Price: £39.95

ISBN: 978 1 84196 265 8

Publisher: Pavilion Press

PUBLICATIONS



Author:
Professor Jim Mansell

Publisher:
Department of Health

Gateway reference:
13814

Pub Date:
2010

Price:
Free
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114346

Raising our sights: services for adults with profound intellectual and multiple disabilities

The report, written by Professor Jim Mansell, and commissioned as part of the Valuing People Now delivery plan highlights the most important parts of planning and delivering support for people with the most complex needs



Author:
Department of Health

Publisher:
Department of Health

Gateway reference:
13521

Pub Date:
2010

Price:
Free
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369

Fulfilling and rewarding lives: the strategy for adults with autism in England

The first autism strategy for England will kick-start fundamental change in public services helping adults with autism to live independent lives and find work.



Author:
Toby Salt

Publisher:
DCSF

ISBN:
978-1-84775-679

D16(8608)/0310

Pub Date:
2010

Price:
Free
<http://www.dcsf.gov.uk/saltreview/>

Salt Review Independent Review of Teacher Supply for Pupils with Severe, Profound and Multiple Learning Difficulties (SLD and PMLD)

The proposals aim to make life easier for parents and help their children maximise their potential. The measures will test easier ways of assessing children with special educational needs (SEN) and there will be new guidance for schools to tackle high exclusions of children with SEN.



Author:
NHS Quality Improvement
Scotland

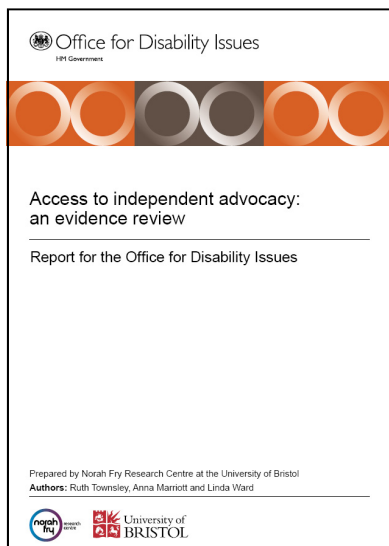
Publisher:
NHS Quality Improvement
Scotland

Pub Date:
2009

Price:
Free
http://www.nhshealthquality.org/nhsqis/files/LD_NOVER_DEC09.pdf

**Healthcare Services for People with Learning Disabilities
Overview of services across Scotland for people with learning disabilities**

Tackling Indifference is a national overview for healthcare services for people with learning disabilities. It is based on the NHS QIS local report for each NHS Board area, and reports on the performance across Scotland against the learning disabilities quality indicators 2 (Promoting Inclusion and Wellbeing and 3 (Meeting General Healthcare Needs).



Author:
Office for Disability Issues

Publisher:
Office for Disability Issues

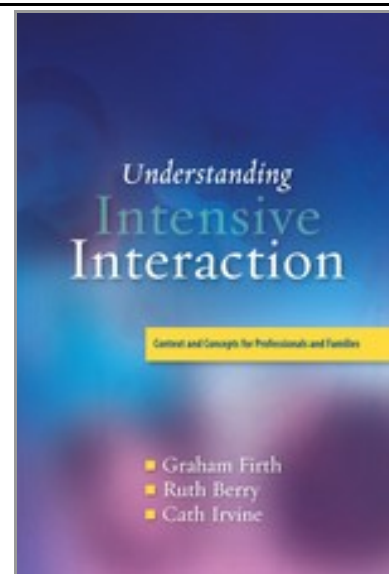
Pub Date:
2009

Price:
Free
<http://www.odi.gov.uk/docs/res/iar/iar-full.pdf>

Access to independent advocacy: an evidence review

This report presents the findings of an evidence review investigating the costs, benefits and effectiveness of advocacy support for disabled people.

The review examined four situations where disabled people are particularly at risk of losing choice and control over their lives



Author:
Graham Firth, Ruth Berry and
Cath Irvine

Publisher:
Jessica Kingsley Publishers

ISBN:
978-1-84310-982-2

Pub Date:
2010

Price:
£17.99

Understanding Intensive Interaction

Context and Concepts for Professionals and Families

Intensive interaction is a valuable approach, with the potential to radically enhance the well-being of difficult-to-reach individuals, such as those with profound and severe learning disabilities, autistic spectrum conditions and emotional problems.

REVIEWS

Title: Understanding Your Young Child with Special Needs

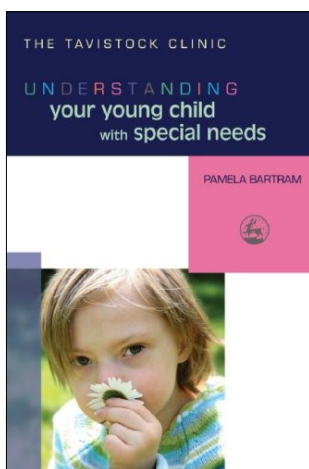
Authors: Pamela Bartram

Publishers: Jessica Kingsley Publishers

Pub date: 2007

Price: £8.99

ISBN: 978-1-84310-533-6



This book forms part of the 'Understanding your Child' series by the Tavistock Clinic. Easy to read, non-judgemental and informative, it would be a valuable resource for all parents of young children with special needs. It will also be of interest to professionals working with families as a reminder of the very difficult, frustrating and sometimes lonely, journey parents often

feel they are on when raising a child with special needs.

As a Consultant Child Psychotherapist, Pamela Bartram has written from a psychoanalytic point of view. She draws on many aspects of family life, highlighting the need for empathy and offering the parent-reader understanding and acceptance of the many emotions, including anger, frustration and guilt that can accompany the birth of a child with special needs. Filled with examples of parenting experiences, the author is sensitive to the uniqueness of each child and family and promotes parental confidence in their expert knowledge of their child.

While providing insights into understanding development and dealing with expectations in relation to a child with special needs, Bartram manages throughout the book to keep in the reader's mind that the most important thing about raising *any* child is that s/he is first, and foremost, a child. Acknowledging, and taking nothing away from, the many challenges faced by parents and carers, she aims to balance the reader's focus in terms of 'ordinariness' and 'special-ness' in relation to stages of development.

The book's conclusion comments on how 'time and the right support', and the 'strength and inner resources' of families can lead to understanding, acceptance, well-being and joy. The appendix has a copy of Emily Perl Kingsley's often-recounted *Welcome to Holland* (1987) as well as suggestions for further reading and a list of helpful organisations.

Pamela Bartram's book is useful as a reference and helpful in terms of keeping perspective and should be a welcome addition to the bookshelf of any parent raising a child with special needs.

Anita Bradshaw
SEN Teacher
Isle of Wight

Website Review

Joy of Sound



Go to the website for the Joy of Sound and see a lovely video of people with profound disabilities enjoying improvised music
<http://www.joyofsound.net/media.html>

Hopefully you will be inspired to have a go yourselves. You don't have to be trained musician to make music. Just go for it!

Short Courses and Conferences

April

Date: 27th
 Title: Conference: Transition Matters. Driving up standards for young people who have complex needs or no sight, in their transition into adulthood.

Location: Deafblind UK Conference Centre, Peterborough

Provider: RNIB

Contact: Sona Molnarova
 See provider details

Date: 27th
 Title: Sensory Differences and the Role of Positive Touch

Location: Birmingham

Provider: Concept Training

Contact: See provider details

Date: 28th
 Title: Physical Interventions Induction Workshop

Location: Kidderminster

Provider: BILD

Contact: See provider details

Date: 28th
 Title: Practical and Effective Ways of Using Multi-sensory Equipment

Location: Edinburgh

Provider: Concept Training

Contact: See provider details

Date: 28th
 Title: How do Children with Special Needs Communicate? A day for Teaching Assistants

Location: Sunfield PDC

Provider: Sunfield PDC

Contact: See provider details

Date: 28th
 Title: Intensive Interaction: using with non-verbal adults and children with autism or profound learning disabilities

Location: Chorley

Provider: Concept Training

Contact: See provider details

Date: 28th
 Title: Success with People with Autistic Spectrum Disorder

Location: Birmingham

Provider: Concept Training

Contact: See provider details

Date: 29th
 Title: Successful Multi-sensory Sessions

Location: Chorley

Provider: Concept Training

Contact: See provider details

Date: 29th
 Title: A multi-sensory and musical 'hands on' taster day – musical and multi-sensory approaches to engage special learners through practical activities.

Presenter: Naomi Rosenberg hosted by Flo Longhorn

Location: London

Provider: Florich Productions

Contact: See provider details

Date: 29th
 Title: Successful Multi-sensory Sessions

Location: Chorley

Provider: Concept Training

Contact: See provider details

Date: 30th
 Title: Sounds Dramatic! Communicating through drama, storytelling and Poetry.

Presenter: Flo Longhorn and Keith Park

Location: London

Provider: Florich Productions

Contact: See provider details

Providers Details

BILD

British Institute of Learning Disabilities

Campion House, Green Street,
 Kidderminster, Worcestershire DY10 1JL

Tel. 01562 723025

E-mail: learning@bild.org.uk

website: www.bild.org.uk

Concept Training

15 Beach Street,
 Morecambe,
 Lancashire LA4 6BT
 Tel. 01524 832 828

E-mail: info@concept-training.co.uk

Website: www.concept-training.co.uk/

May

Date: 5th-7th
 Title: Conference: Positive Behaviour Support
 Location: Dublin
 Provider: BILD
 Contact: See provider details

Date: 6th
 Title: Practical and Effective Ways of Using Multi-sensory Equipment
 Location: Middlesbrough
 Provider: Concept training
 Contact: See provider details

Date: 6th
 Title: Promoting Creativity within the Primary or Special Classroom
 Location: Birmingham
 Provider: Concept Training
 Contact: See provider details

Date: 6th/7th
 Title: Advanced Sensology: reinforcing good practice. Exploring the principles and application of multi-sensory learning in education in-depth
 Location: Bristol
 Provider: Florich Productions
 Contact: See provider details

Date: 7th
 Title: ICT and the Very Special Learner
 Presenter: Ian Bean, Information Manager, Inclusive Technology, Carol Allen, Advisory Teacher ICT and SEN
 Location: York
 Provider: EQUALS
 Contact: admin@equalsoffice.co.uk

Date: 7th
 Title: Very Special Maths
 Location: Sunfield PDC
 Provider: Sunfield PDC
 Contact: See provider details

Date: 10th
 Title: Foetal Alcohol Spectrum Disorders: Implications for practice
 Location: Sunfield PDC
 Provider: Sunfield PDC
 Contact: See provider details

Date: 10th
 Title: Introducing Sensory Integration. Setting up individual 'sensory diets' for optimal learning
 Presenter: Jane Reeves
 Location: London
 Provider: Florich Productions
 Contact: See provider details

Date: 10th
 Title: Creating Exciting Low Tech Multi-Sensory Sessions
 Location: London
 Provider: Concept Training
 Contact: See provider details

Date: 11th
 Title: Responding to the advocacy needs of different groups of people
 Presenter: Elaine Hardie
 Location: Rotherham
 Provider: BILD
 Contact: See provider details

Date: 12th
 Title: Sensory Differences and the Role of Positive Touch
 Location: London
 Provider: Concept Training
 Contact: See provider details

Date: 12th
 Title: Merseyside Partners Training Event. This awareness day is for those based in the North West area who want to find out a little more about postural care training. Organised by Partners in Policymaking
 Provider: Postural Care
 Contact: Anna Waugh
 anna@posturalcareskills.com
 Office: 01827 304 938
 Mobile: 07812 749 892

Providers Details**EQUALS**

PO Box 107, North Sheilds,
 Tyne & Wear, NE30 2YG
 Tel. 0191 272 8600
 Email: admin@equals.co.uk
 Website: www.equals.co.uk

Sunfield PDC

Clent Grove, Clent,
 Nr. Stourbridge,
 West Midlands DY9 9PB
 Tel. 01562 883183
 E-mail: pdc@sunfield.org.uk
 Website: www.sunfield-school.org.uk/courses.htm

Website: www.posturalcareskills.com

Date: 14th
 Title: A PMLD Curriculum for the 21st Century Workshop Leader: Peter Imray, Head of The Bridge School Training and Consultancy Service

Location: Manchester
 Provider: EQUALS
 Contact: admin@equalsoffice.co.uk

Date: 14th
 Title: Intensive Interaction
 Location: The Beeches Conference Centre, Birmingham
 Provider: Interact
 Contact: Helen Janes
 01727 768 726
 07778 178346
events.made.easy@ntlworld.com

Date: 17th
 Title: Communication and sensory assessment. How to support and develop the link between communication and sensory skills
 Location: Manchester
 Provider: Hirstwood Training
 Contact: Email: richardhirstwood@gmail.com
 On-line application: www.multi-sensory-room.co.uk

Date: 17th
 Title: Creating Exciting Low Tech Multi-Sensory Sessions
 Location: Birmingham
 Provider: Concept Training
 Contact: See provider details

Date: 17th
 Title: Promoting Creativity within the Primary or Special School Classroom
 Location: London
 Provider: Concept Training
 Contact: See provider details

Date: 19th
 Title: Yes but ... No but ... Positive risk management in the personalisation agenda
 Location: London
 Provider: BILD
 Contact: See provider details

Date: 19th
 Title: A multi-sensory and musical 'hands on' taster day – musical and multi-sensory approaches to engage special I earners through practical activities.
 Presenter: Naomi Rosenburg hosted by Flo Longhorn
 Location: Manchester
 Provider: Florich productions
 Contact: See provider details

Date: 19th
 Title: The introduction to multi sensory rooms and studios. Unlocking the potential of sensory rooms and studios
 Location: Edinburgh
 Provider: Hirstwood Training
 Contact: Email: richardhirstwood@gmail.com
 On-line application: www.multi-sensory-room.co.uk

Date: 19th
 Title: Successful Multi-sensory Sessions
 Location: London
 Provider: Concept Training
 Contact: See provider details

Date: 20th
 Title: A multi-sensory and musical 'hands on' taster day – musical and multi-sensory approaches to engage special I earners through practical activities.
 Presenter: Naomi Rosenburg hosted by Flo I Longhorn
 Location: Birmingham
 Provider: Florich productions
 Contact: See provider details

Providers Details

Florich Productions

Tel. 01524 42 63 95
 Email: flocatalyst@aol.com
 Website: www.multi-sensory-room.co.uk

RNIB Children's Services

58-72 John Bright Street
 Birmingham B1 1BN
 Tel: 0121 665 4235
 Email children@rnib.org.uk
 Website: www.rnib.org.uk/shortcourseschildren

Date: 20th
 Title: Profound and Multiple Learning Disabilities: Engaging Children in Learning
 Location: London
 Provider: Concept Training
 Contact: See provider details

Date: 21st
 Title: Getting a life, person centred ways to access your community
 Location: London
 Provider: BILD
 Contact: See provider details

Date: 21st- 22nd
 Title: Conference: Profound and Multiple Learning Disability. Meaningful activities to support and engage children and adults with PMLD
 Location: Birmingham
 Provider: Concept Training
 Contact: See provider details

Date: 21st- 23rd
 Title: Sherborne Advanced Practitioners Course (Level 3)
 Location: Sunfield PDC
 Provider: Sunfield PDC
 Contact: See provider details

Date: 24th
 Title: Intensive Interaction
 Location: Sunfield PDC
 Provider: Sunfield PDC
 Contact: See provider details

Date: 25th
 Title: Practical and Effective Ways of Using Multi- sensory Equipment
 Location: Leicester
 Provider: Concept Training
 Contact: See provider details

Date: 25th/26th
 Title: Workshop on Autism: Managing Feelings / Cognitive Abilities / profile of abilities in girls and women with Asperger's Syndrome / Co-morbidity – dual diagnosis of anxiety, depression, bipolar etc.
 Presenter: Tony Attwood
 Location: Santon, Isle of Man
 Provider: National Autistic Society, Isle of Man
 Contact: Andrea Reynolds.
 Email: sreynolds@manx.net

Date: 26th- 29th
 Title: Measures of Progress - Evaluating management outcome in childhood disability. Conceptual and technological advances in the management of children with neurodevelopmental disability have brought about new challenges with respect to evaluation, management and research in habilitation outcomes
 Location: Brussels. Belgium
 Provider: European Academy of Childhood Disability
 Contact: Email: secretary@eacd.org
 Website: www.eacd2010.com/index.php

Date: 28th
 Title: Sensology: Pre-requisites to Learning. An introduction to the theory and practice of multi-sensory learning in education.
 Location: Nottingham
 Provider: Florich productions
 Contact: See provider details

Date: 28th
 Title: Intensive Interaction: using with non-verbal adults and children with autism or profound learning disabilities
 Location: Leicester
 Provider: Concept Training
 Contact: See provider details

June

Date: 4th
 Title: Sensology: Pre-requisites to Learning. An introduction to the theory and practice of multi-sensory learning in education.
 Location: Edinburgh
 Provider: Florich Productions
 Contact: See provider details

Date: 7th/8th
 Title: Advanced Sensology: reinforcing good practice. Exploring the principles and application of multi-sensory learning in education in-depth
 Location: Liverpool
 Provider: Florich Productions
 Contact: See provider details

Date: 8th
 Title: Practical and Effective ways of Using Multi-sensory Equipment
 Location: Dublin
 Provider: Concept Training
 Contact: See provider details

Date: 8th
 Title: The Autistic Spectrum – when things are not straight forward! Working with children with a complex profile
 Location: London
 Provider: Concept Training
 Contact: See provider details

Date: 9th
 Title: Developing person centred thinking and working
 Location: London
 Provider: BILD
 Contact: See provider details

Date: 10th
 Title: Sherborne Developmental Movement Level 1
 Location: Sunfield PDC
 Provider: Sunfield PDC
 Contact: See provider details

Date: 10th
 Title: Practical and Effective ways of Using Multi-sensory Equipment
 Location: Belfast
 Provider: Concept Training
 Contact: See provider details

Date: 10th
 Title: Intensive Interaction: using with non-verbal adults and children with autism or profound learning disabilities
 Location: Birmingham
 Provider: Concept Training
 Contact: See provider details

Date: 10th
 Title: Sensory Differences and the Role of Positive Touch
 Location: Glasgow
 Provider: Concept Training
 Contact: See provider details

Date: 11th
 Title: Evidence Based Practitioner Research – working with children with complex needs
 Location: Sunfield PDC
 Provider: Sunfield PDC
 Contact: See provider details

Date: 11th
 Title: Very Special Maths
 Presenter: Les Staves
 Location: Manchester
 Provider: Florich Productions
 Contact: See provider details

Date: 14th/15th
 Title: Sleep Practitioner Training for health professionals working with families of children with disabilities
 Location: Newcastle
 Provider: Handsel Trust
 Contact: Email: joanne@handseltrust.org

Date: 15th
 Title: Religious, secular and multi sensory approaches to spirituality for learners with special needs
 Location: Manchester Cathedral
 Provider: Florich Productions
 Contact: See provider details

Date: 15th
 Title: Sensory Play and Leisure in the Multi-sensory Environment
 Location: Birmingham
 Provider: Concept Training
 Contact: See provider details

Date: 16th
 Title: Making it happen - implementing the Mental Capacity Act 2005
 Location: London
 Provider: BILD
 Contact: See provider details

Date: 16th
 Title: 'Making sense' of multi-sensory learning. Why and how to create opportunities for effective sensory learning - anywhere
 Location: Birmingham
 Provider: Hirstwood Training
 Contact: Email: richardhirstwood@gmail.com
 On-line application: www.multi-sensory-room.co.uk

Date: 18th
 Title: The introduction to multi sensory rooms and studios. Unlocking the potential of sensory rooms and studios
 Location: Cheltenham
 Provider: Hirstwood Training
 Contact: Email: richardhirstwood@gmail.com
 On-line application: www.multi-sensory-room.co.uk

Date: 18th
 Title: Sounds Dramatic! Communicating through drama, storytelling and Poetry.
 Presenter: Flo Longhorn and Keith Park
 Location: Birmingham
 Provider: Florich Productions
 Contact: See provider details

Date: 22nd
 Title: Religious, secular and multi sensory approaches to spirituality for learners with special needs
 Presenter: Flo Longhorn Keith Park Anne Krisman
 Location: Westminster Cathedral
 Provider: Florich Productions
 Contact: See provider details

Date: 22nd
 Title: Activities for communication for people with profound learning disabilities
 Location: Kidderminster
 Provider: BILD
 Contact: See provider details

Date: 22nd
 Title: Practical and Effective Ways of Using Multi-sensory Equipment
 Location: London
 Provider: Concept Training
 Contact: See provider details

Date: 23rd
 Title: Physical interventions: a policy framework
 Location: Kidderminster
 Provider: BILD
 Contact: See provider details

Date: 24th- 25th
 Title: Emergent literacy and numeracy for learners with sld/pmlD or significant autism
 Presenter: Les Staves and Flo Longhorn
 Location: London
 Provider: Florich Productions
 Contact: See provider details

Date: 25th
 Title: The introduction to multi sensory rooms and studios. Unlocking the potential of sensory rooms and studios
 Location: London
 Provider: Hirstwood Training
 Contact: Email: richardhirstwood@gmail.com
 On-line application: www.multi-sensory-room.co.uk

Date: 25th
 Title: Conference: Assessment for Learning for Pupils with Special Educational Needs and/or Disabilities
 Location: London
 Provider: EQUALS
 Contact: admin@equalsoffice.co.uk

July

Date: 1st
 Title: Strategies to Promote Sensory Well Being: How to make Sensory Integration work at home and school
 Location: Sunfield PDC
 Provider: Sunfield PDC
 Contact: See provider details

Date: 2nd
 Title: Signalong – an Introduction Workshop
 Location: Sunfield PDC
 Provider: Sunfield PDC
 Contact: See provider details

Date: 2nd
 Title: Communication and sensory assessment. How to support and develop the link between communication and sensory skills
 Location: Chester
 Provider: Hirstwood Training
 Contact: Email: richardhirstwood@gmail.com
 On-line application: www.multi-sensory-room.co.uk

Date: 5th
 Title: 'Making sense' of multi-sensory learning. Why and how to create opportunities for effective sensory learning - anywhere
 Location: Bristol
 Provider: Hirstwood Training
 Contact: Email: richardhirstwood@gmail.com
 On-line application: www.multi-sensory-room.co.uk

Date: 6th
 Title: Developing advocacy for people with autism
 Location: Kidderminster
 Provider: BILD
 Contact: See provider details

Date: 7th
 Title: Choosing staff to support you
 Location: Kidderminster
 Provider: BILD
 Contact: See provider details

Date: 8th
 Title: Safeguarding Adults: getting it right
 Presenter: Simon Bickerton
 Location: London
 Provider: BILD
 Contact: See provider details

Date: 12th
 Title: Drama for SEN
 Provider: Sunfield PDC
 Contact: See provider details

LONGER COURSES (with accreditation)

Updated July 2009

MA in Education

SLD1 & SLD2: Pupils with Severe and Profound and Multiple Learning Difficulties (Contexts & Understanding)

This module addresses the requirements of the Teacher Development Agency (TDA) National Special Educational Needs Standards (Core 1a – 1e, Extension 2.i – 2.iv.). It is directly related to the module Curriculum and Teaching – Pupils with Severe and Profound and Multiple Learning Difficulties which addresses further standards. The module provides students with an opportunity to gain an understanding of those influences which impact upon the learning, development and management of pupils with severe and profound and multiple learning difficulties. **Module: EDUM081 For further Details:** The University of Northampton. Tel: 01604 892192. E-mail: admissions@northampton.ac.uk

MA in Education Physical Disabilities: Contexts & Interventions

This module provides opportunities for those with QTS and professional qualifications & experience in services for children to engage in structured critical reflection, exploration of key substantive issues and overarching policy determinants in respect of children and young people with physical disabilities. The module encourages both the development of enhanced understandings of the dimensions of physical disability, with regard to both their theoretical bases and the policies and practices invoked in meeting identified needs. **Module: EDUM058 For further Details:** The University of Northampton. Tel: 01604 892192. E-mail: admissions@northampton.ac.uk

MA in Education Physical Disabilities: Curriculum Issues

This module provides students with opportunities to investigate, critique and evaluate a range of curriculum approaches in the field of PD. It engages students in debates concerning the relevance and practical efficacy of recent guidance & legislation in PD-related issues, and offers an in-depth series of curriculum-focused activity which is intended to enhance both the understanding and the practice of those working with children and young people with PD. **Module: EDUM059 For further Details:** The University of Northampton. Tel: 01604 892192. E-mail: admissions@northampton.ac.uk

MA in Education Understanding Multi-Sensory Impairment

This module addresses the requirements of the Teacher Development Agency (TDA) National Special Educational Needs Standards (Extension 2.i – 2.iv.). It is directly related to Pupils with Multi Sensory Impairment (MSI) The module provides students with an opportunity to gain an understanding of those influences which impact upon the learning, development and management of pupils with multi sensory impairment. It provides professional development for teachers and other professional colleagues working in an area of low incidence need and addresses priorities established by Local Authorities, individual teachers and others working with children and young people who experience MSI. **Module: EDUM054 For further Details:** The University of Northampton. Tel: 01604 892192. E-mail: admissions@northampton.ac.uk

Certificate in Higher Education (CHESL): Supporting Learners with SLD/PMLD

During the course we will be looking in detail at the needs of learners who are known to have severe or profound and multiple learning difficulties. They may also have other additional or associated disabilities, such as physical or sensory impairments. The course will examine topics of both a theoretical and practical nature to provide students with a greater understanding about this group of learners. Together with a broad range of strategies and approaches that can be applied to practice. The sessions will include lectures, workshop activities, discussion and some visiting speakers. **For further Details:** The University of Northampton. Tel: 01604 892192. E-mail: admissions@northampton.ac.uk

BSc in Professional Practice (Learning Disability Pathway)

The School of Health & Social Care, University of Chester, BSc in Professional Practice (Learning Disability Pathway) - includes forensic, mental health/learning disability, challenging behaviour, older person with LD and epilepsy modules (plus others) **For further details:** University of Chester Telephone: 01244 511471 (Pat Palser), 511472 (Monica Davies) or 511473 (Ann Ashford) Email: p.palser@chester.ac.uk, monica.davies@chester.ac.uk, a.ashford@chester.ac.uk

PGCert, AdCert.

Early Years: Sensory and Multiple Needs—This programme begins in January

Distance education.

This programme enables professionals to work more effectively with young children with sensory and multiple needs. Participants may be teachers, who may already hold a specialist qualification in visual impairment, deafness or multisensory impairment; specialist speech and language therapists; health visitors; social workers; carers or others working with young children with sensory and additional needs. **For further details:** University of Birmingham Dr Liz Hodges on 0121 414 4873 or email: E.M.Hodges@bham.ac.uk

AdCert, BPhil, PGCert, PGDip, MEd.**Learning Difficulties and Disabilities (Severe, Profound and Complex)***Distance Education*

This distance education programme has been developed for the range of staff who work with people with severe, profound and complex learning difficulties, for example teachers and lecturers, nurses, therapists, psychologists and support staff.

It is primarily about the learning and development of children and adults with severe, profound and complex learning difficulties, particularly in the areas of cognition and communication. Education, in its broadest sense, is seen as a key topic but other areas covered include health, therapy and social care. An important central theme is multi-agency collaboration and course participants will be expected to develop and reflect on their collaborative work as part of course. All the course assignments are grounded in reflective and evidence-based practice and are driven by the individual professional development needs of participants.

The modules are as follows:

1. Understanding Learning Difficulties and Disabilities
2. Interventions for People with Learning Difficulties and Disabilities
3. Learning Difficulties and Disabilities: Communication and Behaviour
4. Working Together to Meet the Needs of People with Learning Difficulties and Disabilities
5. Learning Difficulties and Disabilities: Life Long Learning
6. Either: Special Studies in Special Education or Practitioner Inquiry in Education

For further details: University of Birmingham Dr Penny Lacey, phone: 0121 414 4878 or email: p.j.lacey@bham.ac.uk

AdCert, BPhil, PGCert, PGDip, MEd.**Multisensory Impairment (Deafblindness) - Distance Learning**

This programme enables teachers and others working in education related fields to work more effectively with learners who are deafblind (multisensory impaired). Some students are teachers working with children or adults, but others are from social services, medical, or residential work. A one-year programme can lead to the awards of Advanced Certificate or Postgraduate Certificate.

- A two-year programme can lead to the award of BPhil, or Postgraduate Diploma.
- A two-year programme with a dissertation can lead to the award of an MEd.

Students working on BPhil or Postgraduate Diploma programmes with some additional activities can, on successful completion, be recognised as meeting the requirements of the DfES for the mandatory qualification for teachers of children with multisensory impairments. **For further details:** University of Birmingham Dr Liz Hodges on 0121-414 4873 or email: e.m.hodges@bham.ac.uk

MSc and Graduate Diploma in Learning Disability Studies -Distance Learning

If you are currently working with people with a learning disability and are interested in updating and expanding your knowledge of theory and practice, this course provides an opportunity to learn alongside other experienced professionals from a wide range of backgrounds.

- Is designed for experienced professionals involved in the care of adults and children with a learning disability.
- Is a distance course, involving the use of specially-prepared texts, annual weekend schools, and local tutorial groups.
- Assesses ability through small practical assignments and a dissertation of 15,000 words based on original research.
- Can be completed in one-year (full-time) or between two and five years (part-time).
- Leads to a Masters of Science degree after the completion of all assignments and the dissertation, or a Postgraduate Diploma for the completion of the assignments alone. **For further details:** University of Birmingham Dr Stuart Cumella, Division of Neuroscience on 0121 414 4507 or email: S.Cumella@bham.ac.uk

Adults with learning disabilities who have significant and complex needs

The School of Psychology at the University of St Andrews offers a Post Graduate Certificate by open/distance learning: "Adults with learning disabilities who have significant and complex needs". This consists of four distance learning modules, chosen from six, and is available to staff with a professional qualification or a first degree.

- Challenging behaviour
- Mental health
- Offenders with learning disabilities
- Older people with learning disabilities
- Profound and multiple disabilities
- Vulnerability, victimisation and abuse

The programme leads to further qualifications at Diploma and Masters level.

For further details: University of St. Andrews <http://psy.st-andrews.ac.uk/people/personal/mc1/>

Dr Martin Campbell email: mc1@st-andrews.ac.uk

Undergraduate and Postgraduate Courses in Profound and Complex Learning Disability

The course is studied by distance learning plus attendance at an Autumn Study School at the University of Manchester.

The course accent is on moving towards increasing choice; developing community presence and participation; and increasing respect for individuals with complex needs. **This approach underpins all aspects of course delivery.**

The course has three aims:

- To support the professional development of people working with children and adults with complex disabilities.
- To empower course participants to advocate for people with profound and complex learning disabilities.
- To enable course participants to develop knowledge and understanding of key issues in the field.

For further details: The University of Manchester, Lesley Jenkins Phone: 0161 275 33337 Email: pld.distance@manchester.ac.uk

Information about the course can also be found on the website: www.manchester.ac.uk/education/pclid

MSc in Advanced Practice (Learning Disabilities)

The School of Health & Social Care, University of Chester, MSc in Advanced Practice (Learning Disabilities) - includes generic modules in research and inter-professional working plus 3 LD specialist modules (socio- political themes in LD; developmental perspectives on LD; profound & complex needs).

For further details: University of Chester

Telephone: 01244 511471 (Pat Palser), 511472 (Monica Davies) or 511473 (Ann Ashford)

Email: p.palser@chester.ac.uk, monica.davies@chester.ac.uk, a.ashford@chester.ac.uk

BPhil, PGDip and MEd Inclusion and SEN

Year 1 Learning Difficulties and Disabilities (Severe, Profound and Complex)

Year 2 Autism (Children) or Autism (Adults)

Distance Education

This two/ three year course contains 6 modules and students study the required number from this list for their chosen award plus a dissertation.

1. Understanding Learning Difficulties and Disabilities
2. Interventions for People with Learning Difficulties and Disabilities
3. Learning Difficulties and Disabilities: Communication and Behaviour
4. Special Educational Needs of Children with Autism or Autism (Adults) Understanding and Working with the Continuum of Need
5. Curriculum and Treatment for Children with Autism or Autism (Adults) Intervention, Care and Education
6. PGDip includes a practical project based on your work

MEd includes a research methods module and a dissertation

For further details: The University of Birmingham, Penny Lacey p.j.lacey@bham.ac.uk or Helen Bradley h.bradley.2@bham.ac.uk

MSc Profound and Complex Learning Disability and Postgraduate Certificate/Diploma Profound and Complex Learning Disability**Distance Learning****Course aims**

- To provide an increased knowledge and understanding of children and adults who have complex needs and/or sensory impairments.
- To empower those directly concerned with this group to advocate for the rights of the individuals concerned. To enable this to happen by providing current information relating to cognitive, emotional, physical, sensory and social needs.

Course Structure

Courses are delivered by Distance Learning over a period of 1-3 years (including an extra year of independent study for MSc. Students undertaking their dissertation). The MSc and Postgraduate Diploma are also available full time (distance learning) over 1 year. The written materials are underpinned by a variety of Study School formats during this time. Student support is also provided by email and telephone contact with the academic tutors. There are no examinations and the course requires approximately 3-4 hours private study per week.

For further details: The University of Manchester, Emma Hardy Phone: 0161 275 3463 Email:

emma.hardy@manchester.ac.uk

Website: www.manchester.ac.uk/education/pclid

PMLD-Link is an informal journal for practitioners and carers working with people with profound and multiple learning disabilities (PMLD), of all ages and in all situations. It is published three times a year and covers a wide range of issues of interest and practical use in the day-to-day work of practitioners, parents and carers in schools, colleges, adult provision, in the home, and many other settings. In recent years the scope of the articles has been widened to include all professions and services, and to cover issues pertaining to all groups, including occasional articles by practitioners and parents from overseas.

PMLD-Link is a grass roots publication and depends on written contributions from parents and carers, teachers, psychologists, special support assistants and workers in all settings. The contributions may be:

- short papers
- news of individuals, families or other groups
- information sharing
- requests from readers for information or useful addresses

PMLD-Link also includes:

- information and reviews of resources or publications and reports on conferences and research
- listings of courses and events relevant to the area of PMLD.

It enables readers to create networks, and provides a forum for contact with others involved in the field.

The editorial team is drawn from a variety of settings and currently includes:

Rob Ashdown	Head Teacher at St. Luke's Primary School, Scunthorpe – a special school for children with complex learning difficulties aged 3 to 11 years.
Alice Bradley	Freelance training and development worker.
Beverley Dawkins	National officer for profound and multiple learning disabilities Mencap.
Julia Dixon	Early Years Advisor and parent of young adult with PMLD.
Ann Fergusson	Family member with learning disability; research and teaching in severe / profound and multiple learning difficulties at the University of Northampton; Research Associate for University of Cambridge <i>What About Us?</i> Project.
Di Foxwell	Coordinator of Clinical Education and Practice Development – BHCT NHS Trust and Distance Regional Tutor for Birmingham University on two learning disabilities programs.
Chris Fuller	Teacher in mainstream and special school with children with PMLD. Founder and director of Bag Books until her very recent retirement.
Penny Lacey	Co-ordinator of the University of Birmingham course in severe, profound and complex learning difficulties; freelance consultant; family member with severe learning difficulties
Loretto Lambe	Director of <i>PAMIS</i> - an organisation in Scotland working with people with profound and multiple learning disabilities, their family carers and professionals who support them.
Wendy Newby	Ten years experience working as a qualified nurse with children with learning difficulties and severe physical disabilities, now teacher and curriculum co-ordinator at St. Rose's School, Stroud and studying for a Masters in learning difficulties and disabilities.
Carol Ouvry	Retired special education teacher, trainer and consultant in the field of PMLD. Previously editor and administrator of <i>PMLD-Link</i> .

There is also a consultation group to assist in commissioning articles from all regions of the UK and overseas and, to ensure a wide coverage of topics. The administrator of *PMLD-Link* is Paul Bramble, The University of Northampton, e-mail: paul.bramble@northampton.ac.uk

Information for Subscribers: *PMLD Link* is published in three issues per year.

Subscription prices for 2009 are:

Annual Subscription	United Kingdom	Outside United Kingdom
Personal/individual	£15	£20
Organisation	£20	£30

(NB. Subscriptions run from January and copies of all issues already mailed this year will be sent)

If you wish to subscribe, or to receive a sample copy of *PMLD-Link* please contact:

Carol Ouvry, *PMLD-Link*, 31 Birdwell Road, Long Ashton, Bristol BS41 9BD. Telephone: 01275 394621 e-mail: carol.ouvry@talktalk.net

Publisher: The University of Northampton

Disclaimer: Views expressed by contributors to *PMLD Link* are their own and do not necessarily reflect the policies and opinions of the editorial team

PMLD Link

IN THIS ISSUE

Guest Editorial: International Issues	Penny Lacey
The development of an Integrated Care Pathway for services to children with complex physical healthcare needs	Roy McConkey and Rosario Baxter
Traumatic Brain Injury in Ireland – An Inclusive Rehabilitative Approach within the Community	Niamh Rowe
Believing in children’s progress: Approaching Maria’s education	Eleni Tragoulia
Education for Children with PMLD in Israel	Naomi Ariel
After School	Edward Khasakhala
Project ‘Shalom’ in Lima, Peru	Jill Gramann
Personnel Working in PMLD in Australia	Sheridan Forster
Links with Holy Trinity School, the Philippines	Dominic Carey
The involvement of young people with learning disabilities in an international conference: moving beyond the factual to challenge our ideas on inclusion	Richard Rose
Persons With Profound And Multiple Learning Disabilities In Japan	Shigeru Suemitsu
The multifaceted condition and collective competence	Peter Limbrick
Future Focus: Sensory Experiences	Chris Fullerton and Di Foxwell