

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

Winter 2004

Assessment

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PMLD LINK relies on contributions from practitioners, parents, carers and everyone interested in the field.

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

GUEST EDITORIAL

Winter 2004

Assessment

Welcome to this bumper edition of PMLD Link! The theme of 'Assessment' has inspired a huge selection of articles and information, highlighting the important part played by assessment as we aim to enhance the lives of people with profound and multiple learning difficulties (PMLD).

The common thread to this issue is the focus of putting the individual at the very centre. This is no easy task. As individuals, professionals, carers or organisations - do we have the skills or the sensitivity to identify and support the very individual ways people with PMLD communicate or learn? Do we have a clear picture of their needs or their interests? Are we being sensitive to their views? What is important to them? What makes a difference? Appropriate assessment can clarify these questions. This collection of articles explores some of these challenges, beginning with a look at Person Centred Approaches (Barbara McIntosh), Spirituality (Marie Broad & Hazel Morgan) and asking people (with PMLD) what they think of their day services (Emma Winn). We begin to see then – what is important to the individual, what makes life meaningful for them?

The article by Jean Ware & Verity Donnelly examines the ways individuals with PMLD learn and offers inspiring 'route maps' as an alternative to the 'checklist' approach. Phyllis Jones explores our understandings of profound and multiple learning difficulties and how this affects our expectations.

Rob Ashdown describes recent government initiatives to encourage more collaborative assessment procedures for children with disabilities. Other articles focus on ways of encouraging greater participation – through music, during museum visits or the use of personalised CDs.

This Winter issue sees the start of a Research page, as a regular feature. We aim to keep you informed of current work relating to PMLD. Some projects are looking for information from families or professionals – maybe you could be involved?

This bumper edition has too much to describe in this short editorial, so just dive in and feel inspired!

Have a great time at Christmas!

Annie Fergusson

Ann Fergusson



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Articles, News, Reports, Letters Spring Vol. 17.2 Issue 51 'Families & Carers'

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The editor of the next PMLD LINK is Beverly Dawkins

The copy date for all articles, information and news for the Spring issue is the 4th February 2005 and the focus is on 'Communication'.

Don't forget to send all contributions to Beverley Dawkins preferably in RTF (Rich Text Format) or 'Microsoft Word' (Beverlys contact details are above). If you are also able to supply photographs and/or images to enhance your article please do so, but it is important that the relevant permission to publish is obtained beforehand.



Future Focus: Communication

By Beverley Dawkins

The next edition of PMLD Link will focus on communication. Both as an ex-speech and language therapist and in my current role as Mencap's National Officer for profound and multiple learning disabilities, communication has been of central importance to my work and so I am very pleased to be the guest editor for this edition. There has been immense progress in supporting those with the most complex communication impairments and we would welcome contributions that illustrate this.

In my work at Mencap I have been particularly excited by the pilot work we have been doing in partnership with the organisation Acting Up on Multi media profiling. The development of computer based personal profiles has enabled service users to have 'a voice' and put across their preferences and choices in a really powerful way. We have been working with front line staff from our housing and support services and this approach has enabled them to learn a great deal about the complex array of communication methods used by the people that they support. I think this missing of communication methods by staff, especially as many staff still do not have access to the training and skills that they need, is a common experience.

Enabling more people to effectively communicate with people with profound and multiple learning disabilities is of crucial importance and underpins inclusion and access to effective support. For example, those responsible for developing Person Centred Planning and introducing Direct Payments are struggling with involving people meaningfully. A recent survey conducted by the Independent Advocacy Campaign found that only 11% of advocacy services feel that they can support someone with a profound and multiple learning disability and that the majority of advocacy schemes felt that they lacked the skills, particularly communication skills, to feel that they could offer support in the future (IAC 2003).

So, it would be great if we could not only hear about the use some of the excellent approaches that have been developed, such as communication passports, and objects of reference, but how you have gone about training others to recognise and value the communication of people with profound and multiple learning disabilities. I look forward to your contributions.

Bareley Dawkins

Beverley Dawkins (Guest Editor Spring Edition on 'Communication') **National officer for profound and multiple learning disabilities.**

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 picture or photos to include we would love to see them (providing we have permissions).

The copy deadline for the next edition is 4th February 2005.

Please send contributions to Beverley.dawkins@mencap.org.uk by post to the address on the previous page.



A PERSON CENTRED APPROACH Can it make a difference to people with high support needs?

Barbara McIntosh Co-Director, The Foundation for People with Learning Disabilities

Summary

This article sets out the basic principles of Person Centred Planning. It considers some of the early lessons in using this approach with people who have complex needs. The article also highlights organisational traits that need to be in place for person centred planning (PCP) to flourish.

Background

Person centred working is a key element of the "Valuing People" strategy. There is currently a great deal of activity in organisations to train and support staff in the implementation of person centred working. At The Foundation For People with Learning Disabilities we have been supporting a wide range of organisations to implement person centred planning (PCP) and to help alter their practice and strategic design to make PCP work. We are undertaking, in collaboration with Lancaster University a three year research programme which is analysing the effectiveness of person centred working in 4 locations across the UK. The research findings will be published in early 2005. This article draws on the learning from all these experiences.

In working to root person centred approaches into our strong professionally driven organisations we face one of the biggest challenges in cultural and behavioural change. The shift in decision making from organisations and professionals to people with disabilities and their families is a fundamental tenet within person centred working. The move to shape support around a person and for it to be in response to the person's wishes, also a trait of PCP, is proving to be a challenge. So...how are we doing and what are we learning?

The Basic Principles of Person Centred Working

It is a highly individual process designed to respond to the expressed needs and desires of the person. There are a number of approaches and they all share the same characteristics. They include Essential Lifestyle Planning, MAPS, PATHS, and Personal Futures Planning.

The key principles of person centred working are:

- Each person with a learning disability is seen to have strengths and abilities to express preferences and to make choices. These may be expressed verbally, through body language or with non-verbal cues.
- These preferences are always central to any action. Person centred support and action are designed to promote maximum independence, community connection and quality of life.
- There is active involvement of the person's social network including family, friends, parents, siblings and people who have shared interests (can be called the Circle of Support). Many new and creative opportunities can arise from this involvement.
- The person's support network/Circle of Support often includes paid staff.
 One person acts as a facilitator and is chosen (wherever possible) by the person with a learning disability.



- A facilitator plays an important role in getting the best from everyone and ensuring that there are positive outcomes for the person.
- The facilitator can be a parent, sibling, friend or paid member of staff. A family member and paid member of staff can work together as co-facilitators.
- The process is not driven by the structure or needs of the organisation but by the disabled person's desire for a better future.
- Time and effort is given to maximize the person's communication and to resolve health issues which inhibit a good quality of life.
- For people who are non-verbal there is an emphasis on bringing together everyone who knows the person and hearing what they understand to be the disabled person's hopes and wishes.
- There is an emphasis on taking positive action and good outcomes (from the person's perspective).
- All meetings of the Circle of Support are held at a time and place preferred by the person.
- The person's Circle of Support or wider network of allies, work with the person to create a plan, set out goals, actions and a time frame. Action to improve the person's life does not have to wait until the plan is finished but can begin immediately!

What Have we Learnt?

The success of Person Centred Planning is highly dependent on families, self advocates and front line staff having a good working knowledge of the process and working together. It takes time and confidence for everyone to move away from assessments and reviews that are driven by the organization towards a process driven by the person, their needs and the views of their family and supporters. It's essential that good training is given to participants, that there is support to facilitators over a long period of time, and that strategic managers are willing to alter the nature of the organisation to achieve actions in response to the person's desires and needs. Experience has shown that it is

important to provide facilitator support on a regular basis and for an extended period of time so that learning can be put into practice. Also facilitators should be supported by their line managers in supervision to discuss and problem solve any issues that arise relating to PCP. The use of Direct Payments and the Independent Living Fund has provided an important catalyst to achieve person centred changes. More information and support to advocates and families to use Direct Payments and ILF is vital.

Other significant areas of learning include:

Communication

Communication is at the heart of PCP. Without effective communication the person is severely limited in making relationships, developing their personality and expressing thoughts and fears. We have found that consideration needs to be given within the PCP process to:

- maximize the person's ability to make choices
- know their signs for yes/no
- present information in a style that can be understood
- understand that the greatest changes will come about with an interactive partner/s who know the person's communication style
- ensure that the person can (wherever possible) see, hear, be comfortable, and is motivated to participate
- know that the disabled person may say "yes" in answering questions as they do not wish to be difficult
- collect and document the signs and signals that the person uses and their unique traits and qualities .Much understanding of the person is lost if parents are no longer involved or if staff move on
- produce a communication book (held by the person) which can give interesting information about the person and help them connect with others in the community



Health Care

People who are unwell may not be motivated to participate. Health Action Planning may be the first step as part of a PCP to ensure the person is fit and well. People who are non-verbal need greater vigilance concerning their health care, given the difficulty in telling us how they feel. One young woman with little spoken language and serious health problems was helped by her parents to create a tape to play to her family doctor to tell him about her difficulties. This was well received and encouraged a better relationship with the GP.

Medical Technology

Increasing numbers of people are dependent on medical technology such as tube feeding and tracheotomies. With careful consideration and sensitivity people can be supported to make decisions and to have the chance for continuous development. Risk taking can be tackled by the person's circle of support through collective decision making rather than be service led.

Good support and training for social care staff is essential for them to have confidence and work in creative ways to support the person to have new and stimulating experiences.

Accessible toilets in community settings
Portable changing tables can be carried by
staff to encourage people to be out and
about. In Nottingham they have constructed
a large disabled toilet with hoists and adult
changing table in the large shopping mall in
the city centre enabling people to be in the
community.

Connection with Community and being seen in a positive light

One of the most important issues is for people to make a contribution and be seen in a positive way. People with high support needs have increasingly been winning contracts to:

Keep the sweet machines filled in a local college

Clean a local cinema

Keep the planter boxes weeded and filled in the High St

Share one job across 11 people, which enables people to work for a few hours every week and retain benefits

One of the big challenges is to ensure that people can work, become a volunteer and make a contribution to their local community. Younger people we have worked with, have been able to try out a range of fast-paced activities despite their wheelchair and their physical disability. This has included downhill dry slope skiing and water skiing!

Meeting People's emotional and relationship needs

Services have not always been skilled at helping people develop relationships which have depth and meaning. Much more time and focus is needed to help people experience friendship and relationships and to prevent depression and anxiety.

Other lessons learnt have included:

- Young people in Transition and their families are at a crucial life changing time. Co-working and real partnership between families and workers can be achieved if families are encouraged to lead the planning process. Some families may not want to create the plan themselves but collaboration with staff is vital.
- Workers in statutory services do not always feel empowered to lead PCP. Bureaucratic processes can prevent change
- Staff from advocacy services and well managed voluntary sector organisations can feel more empowered to help PCP happen than those in statutory services
- Care managers are working to a culture of resource constraint and short term crises which is in contrast to the culture of PCP
- Parental concern, scepticism and caution are common. Parents need pragmatic examples of how PCP will work. Treating parents as real partners and supporting them to lead the process of PCP (if they choose this) is often helpful in creating greater trust



Person Centred working has the potential to improve quality of life for people with complex needs. There is much hard work to do to ensure that people with disabilities,

their families and all staff supporting them understand the principles of PCP, get the right support to implement it and stay focused on positive gains for the person.

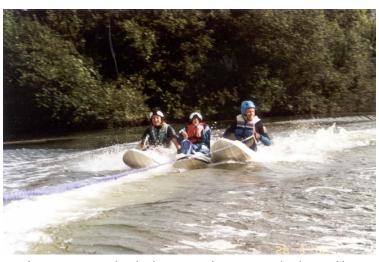
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Carys is 18 years old. About 18 months ago her Mum and Dad decided to join a Person Centred Planning Project.

At the time Carys was attending a special school and living at home. The long term plan was for Carys to leave
School and move into a residential home. Her

family were exhausted, caring for Carys is a 24 hour job.

Carys has some communication difficulties~ she had never been enabled to give consistent yes

and no responses. As she has no spoken communication and has complex physical disabilities this made it difficult to find out what she wanted, what her dreams and wishes are.

Carys had no social life except going out with her family. The family are vely active they enjoy all sorts of sport and have found it impossible to involve Carys in this. They had to take it in turns to do things and care for Carys.

When they planned the first circle meeting they didn't know who to invite. In response to a suggestion from the planning group they sent out invitations to people they knew in the Village, family, friends and people who worked with Carys. They were amazed at the response and had to hold the meeting in the Village Hall. The circle had lots of ideas of things Carys could try and for the first time the family felt that Carys was seen as an individual and not just a severely disabled child.

Since then Cairys has tried out lots of activities, she has been to the theatre, joined a local youth club, joined the Gateway club and participated in the local carnival. Most of this without her Mum and Dad.

Carys has also looked at several Further Education colleges and chosen where she wants to go. This has happened as a direct outcome to her working with a speech therapist to clearly indicate yes and no responses to questions. Carys is enjoying life. This has helped the family, her Dad says they have got their lives back.



Asking people with high support needs what they think of their services

By Emma Winn

In 2001 the Camden Learning Disabilities Service in London went through a review process. Consultation was a key part of this process and the speech and language therapy service was asked to be involved. The service was keen to ask a wide range of people what they thought about services. Therefore this included people with high support needs, who were not able to answer questions about services in a conventional manner. Traditionally this group of people are rarely consulted about issues.

A local day centre was asked if they would like to be involved where 16 people attended. A questionnaire was designed to ask questions about a range of issues that included response to requests for support, activity preferences, how people request support, and whether there is a choice for people to attend the day centre. This questionnaire was demonstrated with workers at the day centre and the carers at home; either parents or key workers.

It was decided that it would be possible to consult the people attending the day centre by observing their non-verbal behaviours when they were there. Out of the 9 questions in the questionnaire, 2 questions were selected as being suitable to observe peoples' behaviour. These were:

- Does the person like going to the day centre? How do you know?
- What activities does the person like doing at the day centre? How do you know?

The aim of the observations was to see if by observing the person and their behaviour in certain situations (ie their arrival at the day centre and their participation in an activity), this would or would not validate the answers provided by carers.

The time available for the observations allowed 5 people to be observed by the speech and language therapist, on 3 separate occasions. The responses provided by the carers to the question -"does (service user) like going to the day centre?" was validated by the observations of the person's behaviour. However, it was not possible to validate the carers' answers to the other question - "what does (service user) like to do at the day centre and how do you know (service user) likes this?". This was due to staffing and timetabling issues at the time of the consultation.

The project showed that it <u>was</u> possible to consult with people with high support needs, so long as the questions being asked are devised in a way that can answered by observing their behaviour. This approach is time intensive but can yield valuable information and validate or invalidate assumptions held about people.

The project was greeted positively by carers and everyone who participated. It was not possible to make observations that would provide information for the whole range of the survey, because many of the questions were not about things that were actually happening (ie activities where behavioural responses could be observed), but were questions about aspects of care that had already happened. Therefore, the service is still dependent on carers' views of what people may think for many areas.

The success of this approach is dependent on the following factors:

- Time this approach takes a significant amount of time
- Key worker/parent knowledge of the person's communication skills
- Observer's knowledge of communication skills but not necessarily knowledge of specific person's communication skills
- Discussion time needed for the observer and the carers



Principal Speech and Language Therapist

The importance of spirituality for people with learning disabilities

By Hazel Morgan & Marie Broad

Why are we here?, a new report published by the Foundation for People with Learning Disabilities, reveals the severe lack of support individuals receive from services in terms of having their spiritual needs met. The report, written by Professor John Swinton and Elaine Powrie of The University of Aberdeen, highlights the importance of spirituality and the implicit need for support from staff and carers.

The report reveals that many people with learning disabilities across the UK are not empowered to recognise or pursue the spiritual side of their existence. Yet all those interviewed (including several people

with profound and multiple disabilities), indicated that they



wanted to explore this aspect of their lives, but often felt unsupported to do this.

Spirituality can be difficult to define and articulate. According to the Dalai Lama spirituality is "concerned with those qualities of the human spirit – such as love and compassion, patience, tolerance, forgiveness, contentment, a sense of responsibility, a sense of harmony – which bring happiness to both self and others."

Supporting people's spiritual needs is not an optional extra for services. As stated in the Human Rights Act (1998) it is a fundamental human right. To overlook the spiritual needs of people with learning disabilities is a serious denial of their rights as human beings and moreover may put emotional well being at risk.

While spirituality includes religion it is something much wider and all encompassing. Spirituality is a relational concept that provides a sense of meaning, belonging, value and hope. In the research process some people were asked 'what is spirituality?' One of the most common answers given by those who used words was friendship.

Interviewer: You said that friends are important – people spending time with you?

Lorraine*: Well that's my opinion. Interviewer: Is there anything else you need to get through life?

Lorraine: I can't think of anything.

We believe it is equally true for those who do not communicate verbally. Staff can support people in making and maintaining voluntary friendships with those around them in the wider community.

Spirituality, is for many, about awe and wonder. A mother described the experiences of her son who has profound and complex needs:

"When he comes to tell us to look at something out of the window it's really special because he doesn't say very much to us. The moon is something he seems to really appreciate. If it's a really bright night and a dark sky and the moon is shining he just has an immense appreciation of that. He wants to stand and look at it for ages and to share that moment of looking at the moon."

There are times when each of us reflects on the world around us, and wants to share this with another. Such moments can be simple joys, yet often there is a deeper sense of being and meaning, which touches on what it means to be human. Sometimes it is just about living in the moment, and sharing and connecting with those around us.

Spirituality can take on greater importance during certain times in a person's life, especially when feelings of grief and loss arise.

Graham*, a 44 year old man with profound and complex needs, experienced his mother's death at 42, after having lived with her his whole life. Graham was taken into



care shortly afterwards and started to become extremely agitated and at times violent. His support worker was troubled by the change in his behaviour and started to investigate what had happened. He discovered that the death of Graham's mother had never been addressed directly with him. On the day of the funeral Graham's family had decided that it would be too upsetting for him to attend. He had been left at home with a family friend that he had never met. Graham's last memory of his mother was peeking through the closed curtains and seeing the family and the hearse move away from the house.

Graham's support worker spent a lot of time with Graham explaining what had happened and allowing him to spend time at his mother's grave. This then enabled the process of mourning and Graham's disturbed behaviour stopped.

Each of us has different ways of coping with grief and emotional stress. But importantly we all need to be given space to grieve and be allowed to let painful emotions rise to the surface. Some may look to their faith to strengthen them at these times and this should be recognised and supported where possible by staff and carers.

For some, spirituality is more centred around a faith perspective.

David* is 22 and has a severe learning disability. He attends a day centre, but for most of the day finds it hard to relax or concentrate for any length of time. He spends a lot of time playing with two spoons or folks and walking around talking to friends. The only time that David sits quietly is when he and his work mates meet in the prayer room. He likes the coloured material on the alter and the burning candle and quiet music. He sits down and leaves his spoons for five minutes. Spending time in the prayer room has helped him relax and feel supported by his friends.

Faith perspectives can help people to focus on what is important in their lives, and help them to seek answers to some of life's difficult questions, like why are we here? Staff and carers can support people in their faiths, for example, by learning about the person's beliefs and arranging for them to

meet with people from a faith community, perhaps a church, synagogue or mosque.

Issues and difficulties surround the area of spiritual care. Staff and carers may feel uneasy about the less rational, more emotional nature of spirituality. Some members of staff might feel that fulfilling the spiritual needs of people with learning disabilities is outside the remit of their services - thinking that perhaps faith communities should cater for the spiritual, while carers deal with caring. Other workers may see the benefits of spiritual care, but feel that there is simply no time in the routine to embrace such diverse and individual needs.

But if spirituality is to be recognised as a vital and fundamental part of human existence, shouldn't spirituality be an integral part of care and support? In 'No box to tick' Professor John Swinton's booklet for carers, the problem of spirituality being at the bottom of the list of priorities for

There's not a box to tick to say 'I have helped Bruce think about mortality.' There is a box to tick to say 'I've cooked the tea' and that 'it was wonderful.'

carers is

highlighted:

So, how can spiritual needs be properly identified and catered for within services and support networks?

It is important that staff and carers really get to know the people they are caring for. Sometimes simply asking what is important to them will reveal deeper insights into who they are and what they believe and hence what they require from support. When a person with learning disabilities has no spoken language, they may require longer to convey their inner feelings. Staff and carers need to be patient and observant in finding out what people enjoy and need. This will often happen through a process of trial and error and through slow relationship building. It is also important that where possible at time of transition, information about spiritual needs should be included. For example, when a person leaves their



family home, information about the person's spiritual needs should be given.

Despite the difficulties in identifying and catering for peoples' individual spiritual needs, not to embrace these needs is ethically problematic. As was illustrated by Graham's story, when deeply spiritual issues are not dealt with adequately, well being is severely jeopardised. In refusing to recognise people's spiritual needs, we are enforcing an anti-spiritual perspective.

Meeting the spiritual needs of people with learning disabilities, including those who have profound and multiple disabilities, needs to be addressed by staff and carers. This is something that must be implemented into daily life, and should take priority alongside physical concerns, such as diet and health.

There is need for further research in regard to people with profound and multiple learning disabilities. We hope that this will be a future focus of the work that continues from the report.

Recommendations

- Carers and support staff must be given training to understand and work with the spiritual dimension of people with learning disabilities.
- Service providers must learn how to be comfortable with the idea of referring people to individuals and organisations who may be better equipped to meet spiritual needs.
- Families must be enabled to have time to support the spiritual needs of their family member.
- Faith communities need to recognise the importance and diversity of faith experienced by people with learning disabilities.

Spirituality concerns all of us; we must not exclude people with learning disabilities and negate this human right. To not provide for people's spiritual needs is equally to impose an ideology, albeit in this instance an anti-spiritual one.

*All names in this article have been changed

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Authors: Hazel Morgan, Co-Director, and Marie Broad, Support Officer, The Foundation for People with Learning Disabilities.

For more information about the spirituality programme, future work, training and publications, please visit www.learningdisabilities.org.uk. For enquiries please call 020 7802 0300 or email fpld@fpld.org.uk.



Assessment for Learning for Pupils with PMLD – the ACCAC Insight Project

By Jean Ware and Verity Donnelly

Anyone who teaches pupils/ students with PMLD will be aware how difficult it is to assess the learning of the most disabled members of this group in a meaningful and holistic way. There are several problems, all of which can seem intractable, namely:

- Knowing what to assess and what to teach
- Getting a sufficiently fine-grained measure of progress (even when a broader view of progress is adopted)
- The complexity of needs experienced by people with PMLD (sensory impairments, significant health problems etc.)

What to teach

Both the importance and the difficulty of decisions about what to teach are often underestimated (especially by those who do not work with this group). In relation to students with moderate and severe disabilities Browder (2001) suggests that deciding what to teach is 'one of the most important decisions we make'. She justifies this in terms of the impact of decisions about curriculum on students' quality of life. We would argue that this impact is at least as great for learners with PMLD. An additional problem for teachers of this group is that it may be very difficult to determine the contribution of teaching to their overall quality of life. One of the initial stimuli to the ACCAC Insight Project was the concern of teachers engaged in a GTCW-funded project on the PSE Framework about how to decide what to teach pupils with PMLD in this complex area. This group of teachers were concerned about entitlement to broader learning of key concepts and wished to avoid reducing the content to a very basic level of self-help skills in which pupils may not ever achieve independence. One critical feature of a 'good' assessment for this group is that it contributes to improving the individual's quality of life, by helping teachers to prioritise learning.

Deciding what to assess and getting a sufficiently fine-grained measure of progress.

The teachers involved in the PSE work also expressed concerns about the difficulty of assessing the learning of pupils with PMLD, a concern that was echoed in a survey of assessment materials used by special schools carried out by LEA advisers in 2002. This survey found that the available materials (InStep, Equals and 'p' levels) were regarded by schools as insufficiently fine-grained for pupils with PMLD. Yet attempts to provide assessments which are sufficiently fine-grained have tended to become bogged down in a myriad of tiny steps, the overall goal of which is easily lost. The drive for accountability and target setting requirements have further encouraged such approaches but , while schools may be able to demonstrate progress via one or more of these small steps, significant developmental/sensory improvements may be missed, because they are not the focus of the assessment. A'good' assessment must avoid this danger, enabling the teacher to keep focused on the medium or long-term goal while being clear about what to teach now.

Complexity of Need

Another major problem in assessing the learning of pupils with PMLD is the impact of motor and sensory impairments, epilepsy and general health on both learning and performance. Variability in health status may lead to large variability in performance, especially with regard to new learning, making assessment of what has been learned problematic. Development may be very uneven, and sensory impairments may make the acquisition of some early key skills much more difficult, and mean that some teaching methods cannot be used effectively. We were also concerned that lack of specific training in the area of PMLD meant that some teachers were



relying heavily on developmental checklists without sufficient awareness of the likely impact of sensory and motor impairments on development, and that such checklists could potentially become a straitjacket rather than an aid.

As Browder points out, what to teach, how to assess progress, and how to teach are inextricably intertwined. For pupils with PMLD the question of what routes are available to reach the next step is crucial given the likelihood of sensory and motor impairments.

At the same time as we were carrying out the PSE project, a colleague who was working with Jean developing teaching materials to develop contingency awareness asked for a 'roadmap' to guide the work. By this he meant a diagram showing the stages on the way to the goal and the variety of routes which might be followed to arrive there. When the idea of developing such a routemap was suggested to the teachers involved in the PSE work they also thought it would be helpful. Thus the ACCAC Insight project was born.

Most assessment instruments, even those concerned with early development and/or designed for learners with difficulties and disabilities assume that children will follow a 'normal' pattern of development . To date most systems have failed to take account of the complex needs of this group of pupils and the interaction between the sensory impairments, motor disabilities and medical problems which many of them experience.

The original aim of the Insight Project was to provide a 'routemap' which was referenced to critical stages in early development, but which showed a variety of routes between the stages and also gave suggestions as to how teachers could assess the pupil's current level of functioning and how they might help pupils move from one stage to another, while taking account of the complexity of pupils' needs. Such an assessment we felt could potentially fulfil the criteria for a good assessment.

In designing it we took into account a number of key principles. The materials should::

- •Promote equity all learners are entitled to have their needs met
- •Involve/empower pupils, families, teachers, multi disciplinary teams
- •Be founded in research
- Consider the impact of the environment
- Have regard for relationships
- •Provide a picture of the whole learner and the learning process
- Emphasise essential skills as a foundation for later learning
- Support accurate judgements & promote consistency
- •Support staff to find evidence of understanding & development to enable best possible progress

The materials are not designed to be used as a checklist and nor are they intended to form a curriculum for these learners. Rather they present a range of possible learning pathways for staff to consider. Over reliance on small steps from checklists may distract from the key focus on individual priorities and may narrow the curriculum taught. The materials aim to encourage a focus on the learning process and consideration of lateral as well as hierarchical progress. They are designed to be used flexibly to allow staff to observe each individual's approach to learning, and to support a focus on important cross-curricular skills such as learning to learn. The materials currently consist of an introductory booklet, a route map, showing key milestones in early cognitive development and communication/ social interaction and more detailed pages for each milestone. The booklet contains questions designed to help schools meet the

in early cognitive development and communication/ social interaction and more detailed pages for each milestone. The booklet contains questions designed to help schools meet the challenge of including pupils with very profound disabilities within a common curriculum and discusses ways of maximising learning based on recent research in areas such as psychology and neuroscience. The routemap, together with the more detailed pages provides suggestions for assessment and teaching. Use of the map encourages close observation, not only of achievements, but of sensory function and preferred channels of learning.



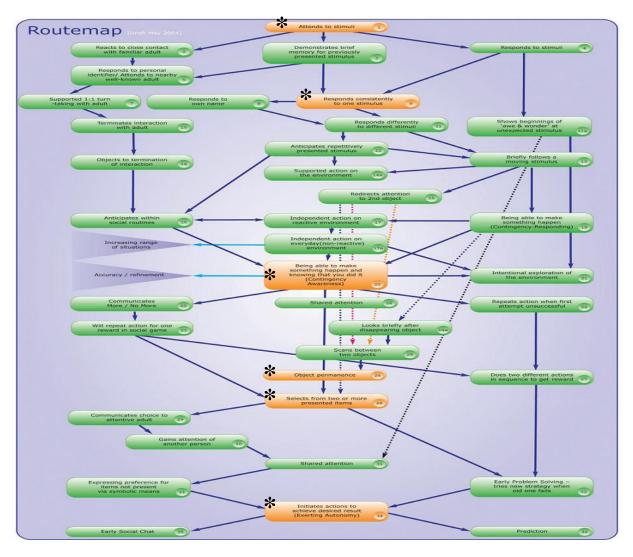
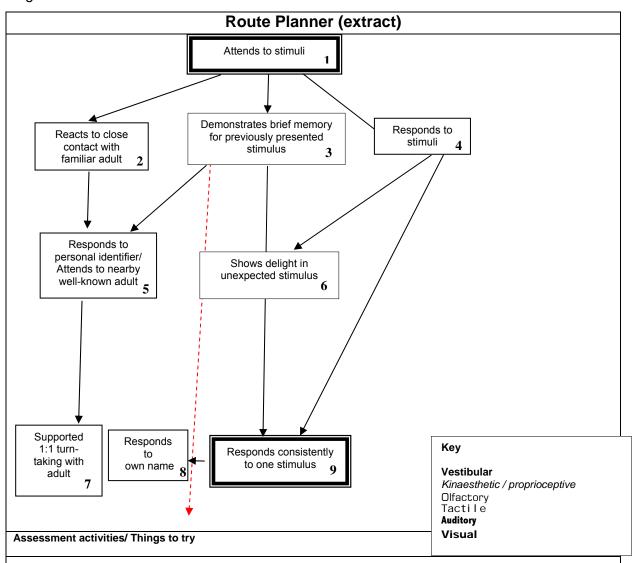


Figure 1 shows the Routemap. The orange boxes (see *) are key milestones in communication/ early cognitive development. In order to use the chart to assess a pupil you start at a step you know they can already do, and work down through the steps until they do not respond The routemap then shows a number of possible learning pathways to the next major 'junction'. This encourages the adoption of problem solving approaches, for example when barriers to learning are encountered. The design of the routemap helps draw attention to lateral as well as hierarchical progress, for example box 17a 'Independent action on everyday (non-reactive) environment' has an arrow indicating that one way in which progress may be observed from this point is in the pupils acting on the environment in a wider range of situations. Similarly at box 20 progress may be observed through 'increasing refinement'. For example, a pupil who activates switch-operated toy on their wheelchair tray with a large swipe involving the whole of their upper body may refine their hitting so it involves only their forearm.

The detailed pages provide further support, suggesting activities which can be tried during the assessment, responses to look for and teaching strategies to help the pupil move on (See Figure 2). So for a pupil at a very early stage of development who is known to attend to a few stimuli and react to close contact with a familiar adult, the teacher might both look for more pronounced responses to stimuli (Box 4) and look for attention to a nearby familiar adult (Box 5) employing the suggested teaching strategies if no response was observed (Figure 3)



Figure 2



- If no obvious response, then try videoing the assessment activity.
- Try to find out which are the learner's strongest senses. Use these first in future activities, but continue to offer other sensory experiences too.
- 1. Rock or swing learner gently, then pause

Present vibration, eg. Massager or vibrating cushion.

Lipstick smear of taste on learner's lips

Place learner's hand on fur-covered water bottle

Play music or familiar song, musical instruments

Present torch reflected on a shiny surface. If no response, try moving it a little bit

- 2. A familiar available adult holds learner and: Talks or sings, leaving pauses for response
- Present stimulus to learner. When learner stops attending, immediately remove and re-present stimulus (gap should be less than half a second). Use a stopwatch. If learner attends less long to second presentation, it is likely that learner has remembered the stimulus. (You may need to try this several times to be sure).
 NB. Stimulus should be neutral (not face of familiar adult, not food).

Try a black & white chequerboard.

- 4. Present stimulus to learner in a similar way to 1. above. Use information you have gathered about preferred sense modalities and record outcomes which should be more pronounced than attending.
- 5. Try new tastes- lipstick smear
- 6. Try vibrating cushion/ resonance board, water bed
- Present different textures e.g. warm sand which pupils can engage with apply to different parts of the body.

Try musical instruments, tapes, musical toys. Use peep-bo, puppets, pop-up toys



Things to look for

1&2 Look for any change in behaviour which are not reflex responses eq:

Stilling (momentary pause)

Turning (head, eyes, or body)

Lip / tongue movement

eye flicker

change in breathing.

Tensing or relaxing (you may need to be in close physical contact in order to perceive this).

NB. The Affective Communication Assessment (ACA) may help you to structure your observations

3. Decline of interest when stimulus is repeated. Look for recovery of interest when new stimulus is offered.4. Look for:

change in activity level,vocalising, open mouth/move tongue moving fingers, eg. in sheepskin

kick.

Teaching strategies

For any stimulus in any modality try on/off pattern.

When no response is observed, make stimulus more salient, Increase contrast between stimulus and background.

See page x of booklet for additional information on touch.

Consult sensory services for advice.

1.Using 2 staff, one supporting the learner in a sitting position and one in front pulling gently back & forwards and then pausing. Try different parts of the body (soles of feet, back of neck may be more sensitive areas).

Try moving the learner's hand (especially fingertips) in sheepskin, gel, warm water, etc.

Try sounds of different frequencies, timbre, duration In a darkened corner, present a repeated pattern of stimulus, no-stimulus (light, no light). (eg. RNIB software "Just Look?")

2. Choose learner's strongest sense to start.

Touch/ctroke face/hands.

If learner responds best to auditory stimuli, try talking and singing close into learner with pauses for close observation of possible responses

If learner responds well to visual stimulus, try getting close in and exaggerating your facial expression. If no response, try exaggerating your features with face paint or sun block, luminous wig, glasses etc.

3. Increase gaps to look for evidence of short term memory (see booklet page x –habituation)

Use variety of stimuli

Show new stimulus, rather than same stimulus again. Look for recovery of interest.

4. Increase the range, complexity and variety of stimuli used in 1. above. The level of prompting / exaggeration used should be gradually reduced to a more natural level.

If the pupil has only shown a response in one sense modality up to this point, then you should seek to extend this to other available senses. Consider your positioning in relation to learner's visual field/auditory ability etc (refer to booklet page x)

Figure 3

Assessment activities / Things to try

5. Sit close to learner - hug/touch

Move towards learner speaking/singing.

Draw attention to particular features eg. exaggerate facial expression, feel long hair, smell perfume, say name

7. Support learner in rocking game e.g. row the boat Support the learner to coactively push the ball to adult/return In conversation, take turns - talk and wait for "reply"

Present/represent toy/object (visual/musical/vibrating) taking turn for self

One for you – one for me – sharing raisins/ toys etc

- 8. Call learner by name try to avoid giving additional cues
- 9. Present familiar visual/auditory/tactile/other sensory stimulus which has been used consistently with the learner. Repeat in the same way several times.

Teaching strategies

5. Ensure all staff in regular contact with learner have personal identifier/action e.g. stroke on cheek/distinctive watch

Encourage recognition of voice – use learner's name on approach, talk using consistent language

For pupils with VI/HI a personal, tactile sign may be used.



These materials are currently being trialled by 15 schools in Wales and feedback so far has been very positive. For example one school reported that using the materials had enabled them to identify both that different members were making different judgements about a pupil's behaviour and that the child's behaviour varied according to both the time of day and the member of staff involved. Another school highlighted the identification of gaps in early development and the limited range of situations in which pupils could perform certain behaviours. We hope that use of the materials will encourage greater consistency between staff and help them to develop a system of recording which is both manageable and useful for informing future learning.

Further development will take place during 2005, and it is hoped that the materials will be available early in the 2005-6 school year. It is anticipated that the final form of the materials will be as a multi-media package, consisting of a poster of the routemap, a guidance booklet and a DVD which will also include video clips to support consistent assessment.

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INTERCONNECTIONS ELECTRONIC BULLETIN

ABOUT CHILDREN WITH DISABILITIES / SEN

CONTENTS -

- 1. About this Electronic Bulletin
- 2. News from central government
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- 8. The Keyworker: A question.
- 9. The Keyworker: A really big question "How viable is your multi-agency keyworking project?"
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Some relevant reading -



- 15. One year distance education programme: Early years: Sensory and Multiple Needs
- 16. Bromley Early Support Programme invites you ...

1. About this Electronic Bulletin

It comes from me, Peter Limbrick, in Interconnections. I am an independent consultant to statutory services in the field of babies and children with disabilities / SEN. I specialise in children with multiple / complex needs and have developed the Team-around-the-Child model for supporting children and their families.

The Electronic Bulletin goes free to over 3,500 people in all parts of the UK and Ireland and then finds it way into many other networks and countries. The Interconnections electronic address list includes people from health, education and social services, the voluntary and private sectors, parent organisations, research organisations, campaign offices, etc. People who receive the bulletin are welcome to forward it to their own colleagues and networks and to use the information in newsletters and bulletins as long as the Interconnections electronic bulletin is acknowledged.

Information in the bulletin can include -

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- News of government initiatives
- Information about forthcoming conferences, meetings and events
- Features about examples of good practice and innovative work
- Summaries of research findings
- Questions to which people are seeking answers
- Information about small organisations and campaigns
- Occasional job vacancies

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The electronic address list. Please let me know when you want to add, remove or alter a name on the list. This can be done by e-mail, telephone, fax or post.

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For more information and the full electronic bullet in please see the details above



Teachers' understandings of pupils with profound and multiple learning disabilities and the possible impact on assessment in the classroom

By Phyllis Jones

It was with great interest that when I read recent editions of PMLD Link that have reminded me about the spirit of Valuing People with Profound and Multiple Learning Disabilities (2001), and the importance of becoming more aware of the impact of the views we hold about people with profound and multiple learning disabilities. This relates directly to a project I have been involved in that explored teachers' views about their pupils with profound and multiple disabilities. The project has implications for assessment, as assessment is so intertwined with belief systems. What we assess is driven by how we understand. For example, it is clear in the literature that the crucial role of communication in the curriculum for learners with profound and multiple learning disabilities is an accepted belief (Ware 1994, Lacey and Ouvry 1998). However, concerning communication, what and how we assess communication is dependent upon our understandings of profound and multiple learning disabilities, and also our understandings of the development and nature of communication. In the late nineteen eighties, when I was teaching in a 'special care' class. I experienced a subtle shift in my approach to teaching communication. The affective communication work of Kiernan and Reid (1987) influenced my understanding of the nature and role of communication, while my work in the classroom strengthened my belief that young people with profound and multiple learning disabilities have wonderful systems of communication that I was still struggling to understand. I felt comfortable that the Affective Communication Schedule was helping me to understand my pupils better, so I used it extensively. In such a way, our belief systems naturally impact on our assessment and teaching.

This current article aims to give an insight into some of the findings of the project as they relate to teachers' understandings of profound and multiple learning disabilities. More comprehensive articles are either

published (Jones, 2004) or in development. The study was a four year project with fourteen teachers of pupils with profound and multiple learning disabilities; the teachers live and work in the North East of the United Kingdom. At the time of the research all the teachers worked in segregated provision. There were a variety of contexts for teaching, including integrated classes in a special school, segregated classes for pupils with profound and multiple learning disabilities in a special school, early years' classes and classes for young adults. Thus the sample group may be representative of teachers working in segregated provision, but not teachers working in a more inclusive provision in mainstream education. The research design centered upon questionnaires and individual and group interviews, as data collection processes. At the outset of the project the teachers completed a questionnaire that asked them about their professional experiences and formed the basis of the individual interview. In the questionnaire they detailed qualifications, teaching experience and professional development. The individual interviews were semistructured. During the interview teachers talked at length about their training and qualifications, professional development experiences and personal encounters of disability. The interview ended with teachers talking about influences on their understanding and practice. Two stages of three small group interviews then took place. The focus of the first group interview was a video of three pupils who are defined in their Statements of Special Education Needs as having profound and multiple learning disabilities, but who present as very different learners from each other. The teachers did not know any of the young people in the video and were asked to talk about how the pupils helped them to understand profound and multiple learning difficulties. The direction of the discussions was decided by the teachers themselves. The second group interview centered upon



the teachers' views of the impact of society on their work. At each stage of the research process the teachers were able to respond and reflect upon the interpretations of the data to date. During the final group interviews teachers were presented with a synopsis of the themes emerging from the data analysis so far and they were given the opportunity to reflect and discuss these among themselves and with the researcher.

Throughout the different stages of the project the teachers offered very similar views about their perceived notion of the nature of profound and multiple learning disabilities. It is clear that they talk about a group of pupils with *complex* and *multiple* learning disabilities. Pupils who can be very *different* from one another, who may present as very *individual* and *unique*, who may share common characteristics, but whose individual pictures are very difficult to define in a group definition. This was summarised by one teacher:

"It's hard to describe a typical child because they're often very different, they can be ambulant and mobile, they can also be profoundly disabled"

Interview 9

The descriptions offered by the teachers suggest there are three main elements to their views of profound and multiple learning disabilities. These are:

Neurological issues

Teachers talk of neurological damage that may have created the profound and multiple learning disabilities:

"Little people who have been damaged usually at birth or sometimes by an accident"

Interview 10

"Significant damage to different parts of the brain"

Interview 9

They appear to view this group of learners as incurring some neurological damage, usually from birth. This relates to professional understandings of profound

and multiple learning disabilities (Orelove and Sobsey, 1996, WHO, 2001). If there is a belief that damage has occurred, teachers may well see assessment as a way of understanding, identifying and compensating for the damage.

Developmental issues

Aspects of early development emerged as central to the teachers' descriptions of this group of pupils; these include the areas of cognition, communication, sensory, physical and social/behaviour. It becomes clear that the teachers are talking about very early stages of development:

"We're looking at a huge baby really"
Interview 1

All but one teacher marked the capacity of cognitive functioning and intellectual reasoning as a possible distinguishing element of profound and multiple learning disabilities:

"I think its got to start with the brain, you know the level of cognitive functioning determines profound as opposed to severe" Interview 4

Teachers highlighted how aspects of development make up their understanding of profound and multiple learning disabilities. A focal point of such development is cognition and, for some teachers, communication too. This is reflected in the literature on early developmental factors in pupils with profound and multiple learning disabilities (Ouvry, 1987, Tilstone, 1991, Ware, 1994. Orelove and Sobsey, 1996). It also, in some ways, helps to explain the continued focus over the years on assessments of early stages of development for learners of all ages with profound and multiple learning difficulties.

Co-existence issues

All the teachers in the project made reference to the multi sensory impairment that they believe compounds, or adds to, the nature of the learner's difficulties. Notions of complexity of disability emerged



in the interviews when teachers talked about how it may sometimes be difficult to ascertain a principal difficulty due to a combination or co- existence of numerous disabilities:

"It's probably, although not always, a complex arrangement of disabilities, layering on top of one another but are quite hard to disentangle"

Interview 3

while another talks about:

"Complex learning difficulties that impinge on each other"

Interview 9

supported by another who said:

"We would almost, but not always, be looking for children with sensory deprivation, deaf blind, compounded with cerebral palsy"

Interview 1

Again, the teachers are affirming published professional literature relating to the co-existence of multiple disabilities for this group of learners (Lacey and Ouvry, 1998, SCAA, 1996).

Understandably, the discussions of the teachers closely reflect the professional literature. They are trained professionals and operate in a professional world; their frames of references are professionally based, something we would demand of them as teachers. Naturally, the way teachers understand profound and multiple learning disabilities will have a impact upon the way assessment processes are adopted and interpreted in the classroom. It can be interpreted from this project that teachers may have higher levels of comfort with assessment processes that have a neurological and developmental emphasis. It also confirms what we already know, that assessment for learners with profound and multiple learning disabilities is a highly complex and multi layered process: a process that requires a high level of understanding about profound and multiple learning disabilities, as well as about the curriculum to be taught. It is important however not to be misled by professional talk of neurological damage, developmental delay and co-existence issues. It must not be forgotten that thirty years ago this group of learners was classed as ineducable.

whereas today, through these interviews, we hear teachers discussing in detail the individual learning needs of their pupils:

"The same educational philosophy applies to a student with pmld as to any other student in the school; it's all the same processes and procedure."

Interview 4

and.

"Everyone can learn and we shouldn't just be doing, we should be developing."

Interview 7

We also know that teachers are continually engaged in a struggle to find and apply sensitive and appropriate assessment processes to the teaching and learning that occurs in their classrooms.

However, this project also raised some challenging issues, one of them relating to parental understandings of children with profound and multiple learning disabilities. A brief appraisal of parental literature highlights possible differences between the way teachers and parents talk about young people with profound and multiple learning disabilities. There is a substantial amount written around parental involvement but relatively much less in relation to their perspectives and their understandings of their children. Indeed, Ball (1994) raised concerns about the dominance of a professional discourse in our understandings of disability. In reflecting upon some of the parental literature difficult issues emerge. Fitton (1994) offers two different descriptions of her daughter, who has the classification of profound and multiple learning disabilities, one for professionals and one for friends. The professional perspective stresses the negative problems that her daughter so clearly had: the fits, the physical deformities, the feeding problems. The second perspective intended for friends stresses her daughter's positive attributes: her sense of humour, her communication strategies, her mischief, her preferences. On reading both descriptions it would be easy to assume that they were two different people. Another mother reveals, through a published poem,



her anger at professionals for making assumptions about her son (Murray and Penman, 1996). Her poem illustrates that, although parents are identifying characteristics to describe their children. they are not the deficit based characteristics they believe teachers employ. There are some examples in the literature of teachers talking in this more positive way. Lacey and Ouvry (1998) present one teacher who describes one of her pupils with profound and multiple learning disabilities in a similar way to how Fitton (1994) described her daughter to her friends and family. The teachers' views in this project were generally much more akin to a professional perspective rather than a parental one. This could indeed be more of a reflection of the research design for the project rather than a true reflection of the teachers' views, but it does highlight some level of mismatch. This, I believe, presents a major challenge to teacher educators. We need to ensure that more current understandings of disability and profound and multiple learning disabilities, as reflected in the developing social theories of disability, updated classifications of profound and multiple learning difficulties (WHO, 2002) and

parental perspectives are transferring to the school and classroom context. Teacher educators need to be influencing the continued development of teachers' frames of references. Teachers of pupils with profound and multiple learning disabilities need to be supported to consider more contemporary theories of disability and to make sense of these theories in their classroom contexts. Why? Because inherent in these more contemporary perspectives is a different way of valuing people with profound and multiple learning disabilities. These perspectives advocate the need to respect the contribution of people with profound and multiple learning disabilities to our communities and to our ultimate well being as a society. This suggests the need to give greater credence to parental perspectives in professional development that will ultimately give teachers permission to talk about this group of learners differently and to continue to develop their understandings of profound and multiple learning disabilities. When this happens, subtle but important changes in the assessment processes adopted and interpreted in the classroom should follow.

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The Common Assessment Framework

By Rob Ashdown

In its Green Paper of September 2003, "Every Child Matters", the Government proposed the introduction of a Common Assessment Framework (CAF) as a crucial element of the Government's strategy for integrating education, health and social care services for children, young people and their families. In late August 2004, the Government launched a consultation inviting comments on a proposed CAF from anyone involved in working with children. By the time of the publication of this issue of *PMLD Link* the consultation period will be finished and the CAF materials and an implementation plan should be published. The expectation is that implementation will take place in a first wave of local authorities from April 2005. Implementation for all other authorities will take place in 2006 – 2008.

Most agencies and practitioners who work with children and young people with PMLD conduct various types of needs assessment to determine what services should be offered in each case. Unfortunately, each agency has its own approach to assessment and, often, there is a lack of coordination and consistency between them. It is not unusual to hear stories of important needs not being identified early enough or being missed altogether. A common complaint of parents is that different agencies ask families for similar information time and time again. Moreover, time and resources may be wasted by inappropriate referral to agencies, particularly social services, with inadequate needs assessment being done first. The worst aspect of this is that family expectations are raised only to find that the child/young person does not qualify for any support.

The Government's stated aim is to improve the consistency and quality of assessments by introducing a national, common method of assessing the needs of children and young people that can be used by all agencies working with them. The beguiling vision is of a CAF that provides a thorough assessment approach that may be used at the first sign of needs and that this will establish referral routes for appropriate support. The CAF will not replace all other forms of assessment: in the jargon of the consultation document, the CAF would function as a *common front-end* to more specialist assessments.

Over the past few years the potential benefits and demands of a CAF have been demonstrated through a local initiative in North Lincolnshire unitary authority. North Lincolnshire is a small authority centred on the industrial town of Scunthorpe and the surrounding small towns and villages of a rural hinterland with a total of population of about 150,000 people, 20 per cent of whom are children. The local authority and health services trusts have collaborated to develop an 'interagency assessment of children in need'. This assessment tool is based upon the Framework for the Assessment of Children in Need and their Families which was published in 2000 by the Department of Health.

The interagency assessment tool gathers information about three dimensions that impact upon the child's safeguarding and welfare: the child's developmental needs, parenting capacity for meeting the child's health, educational, social, personal and emotional needs, and a range of family and environmental factors. The assessment tool is banded for children aged under five years, five to nine, ten to fourteen and over fifteen. There is even an assessment for the unborn child. In the case of children with learning difficulties, the expectation is that the persons completing the assessment would use the assessment tool that is appropriate to their chronological age rather than their developmental age.

The following sets out the kind of information that is gathered using the example of the assessment tool for a child aged 5 to 9 years. The initial pages record



basic information about the child, the agencies which are currently working with the child/family and the child's principal carers. Other key information is recorded about the child; Is there a learning disability? chronic physical illness or disability? significant medical history? mental health problem? registration on a disability register? registration on the child protection register? Has the child ever been looked after by a local authority? In each case, if the answer is Yes, then a record should be made giving details including what support has been offered or is being offered.

The rest of the assessment is designed to examine the various dimensions. For example, the assessment of the child's health needs asks the following questions: How far are the parents able to meet the child's health needs? To what extent do wider family and environmental factors impact upon the child's health needs? Do you have any concerns about the child's developmental progress in this area? How could the child's family or the immediate community meet the need identified? Which, if any, of the needs identified above require referral to/assistance from voluntary or statutory agencies? What is the parent(s) view of this dimension? What is the child's view?

For each dimension examples of key indicators of need are shown. These are not a complete list but are intended as a guide to show the sort of questions that should be asked. The key indicators are grouped according to the classification of mild need, moderate need or serious need. Mild needs are recorded but, in isolation, they normally would not be expected to require provision of a service. Indicators of moderate need show that services are required, possibly from a range of agencies within a specified timescale. Serious needs mean that services are likely to be required immediately from a range of services. This will lead to referral to Social Services who have the responsibility for leading and coordinating action in such circumstances.

In the same way indicators of concern and pertinent questions, relating to child

development and parenting capacity to meet needs, are listed on several other pages for the following: the child's physical and social environment; education; identity and social presentation; family and social relationships; and emotional and behavioural development and self-care skills.

When the person doing the assessment has completed each of the assessment dimensions, they have to fill in a summary section. The assessment tool concludes with a summary of work to be undertaken to address concerns or unmet needs. The person doing the assessment only completes the plan if their agency will be meeting these needs or will be taking a lead responsibility. There is no way that, for example, a teacher might specify action to be undertaken by Social Services.

Copies of the form are kept by the assessor, the family, any other agency to which the family may be referred and to the Common Assessment Development Coordinator. The latter ensures that children are not repeatedly assessed and, therefore, agencies with concerns need to check with the coordinator before initiating common assessment.

The various agencies in North Lincolnshire, in consultation with parents and practitioners, have spent al lot of time and effort on the design of the assessment tool to ensure that it is practical and useful. North Lincolnshire is a Children's Trust Pathfinder and the lead directors to all of the statutory agencies have committed their staff to using it. A comprehensive training programme has been rolled out to a range of managers and their staff within education, health and social care services. However, it still possible to encounter people who have no awareness of the process or their obligations under it.

A fundamental principle is involvement and empowerment of the child and the parents in the needs assessment. It is important to share the form with these people and making sure that they understand what it entails. Moreover, the assessment has to be presented as a way of identifying where



families need help rather than finding out in which ways they have failed. Filling out the form calls for partnership with parents and carers and, ideally, completion of the assessment in the child's home. The aim is to reach a shared understanding of what is happening and the impact on the child. The assessment tool also provides opportunities for the parents to express their views, including any dissent with the conclusions made by the assessor at the end of each assessment section. The whole approach is a non-judgemental one and this demands certain skills of assessors: they need to be sensitive to racial and cultural variations; they need to be aware of barriers to social integration of families with a disabled child or young person; they need to be aware of the implications of disabilities for child development and for families; they need to be capable of objectively recording evidence rather than their own assumptions about need; they need to be good listeners; they need to be innovative when trying to elicit the views of children and parents with communication difficulties; and they need to show genuine interest.

Rarely, some parents disagree with the assessor's perceived need to make a referral to another agency and explanation of the benefits has to be carefully given. In such cases, the assessor may only go against the family wishes where there is a significant risk of harm to the child or others.

When the assessment is completed, the assessor has five options for further action:

- 1. No further action required
- 2. Identified needs to be met by the assessor's own agency
- 3. Referral to Social Services
- 4. Referral to agencies other than Social Services
- 5. Consider a Child in Need meeting

If an assessor forms a judgement at any point in the process that there is a child protection issue, they must immediately refer the case to the Social Services. However, if there is no child protection issue but there are complex and sustained needs that require a coordinated multi-agency response, the assessor, or the assessor's

agency, should call a Child in Need meeting. The parents must agree with this and there must be reference to the designated persons within the agency (there are designated person for each agency) who can provide support and advice about the process of arranging a meeting. The meeting should be minuted and should result in a plan of action detailing what is expected from each of the contributing agencies. Preparation for this meeting or action afterwards may call for additional specialist assessments but the services conducting these should not have to ask the questions already covered by the common assessment process because this information should be available to them.

In the case of a child or young person with PMLD, the number of the people who may need to be involved in the Child In Need meeting can be large. Our experience of convening one recent meeting is fairly typical: the child's needs and the family's needs were such that the people who had to be present included the parents, a community nurse from the local Learning Disabilities Team, a dietician, an Educational Welfare Officer, a representative from Council's Housing Services, a designated social worker, a teacher, a consultant paediatrician, an occupational therapist and a physiotherapist. The school secretary functioned as minute taker and the Deputy Head chaired the meeting. Because St. Luke's is a primary special school and the pupil was a Year 6 pupil, there was also a representative of the secondary special school present.

The Government envisages that the CAF, together with the information sharing databases proposed in the Children Bill, will serve to deliver a more coherent service to children and young people. Databases have the potential to make CAF information available to all practitioners and will enable them to contact one another and share assessment information. Security of confidential information is an issue, of course. It is envisaged that the content of the common assessment would not be included on the database but will be stored on agencies' own secure systems.



North Lincolnshire's Pathfinder management group have ensured that all agencies sign up to its approach to common assessment. However, it will be some years before Children's Trusts become wellestablished in all areas. In the meantime, the Government has set out its expectations quite clearly. For instance, the National Service Framework for Children, Young People and Maternity Services makes plain to Primary Care Trusts and other local health agencies the importance of the CAF if children's health services are to develop early interventions which take account of the child's holistic needs. As made plain in

Every Child Matters schools will have a critical role too in using the CAF and promoting collaboration between schools and specialist services across all agencies. These are new roles for these bodies and, obviously, a great deal of coordinated work will have to be done to develop effective interventions. Databases and new training packages are costly developments and there are human resources costs too, and, doubtless, agencies and staff will be conscious of limitations posed by financial and other constraints. However, we are moving into a new era which promises much.

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Assessment of Museum Education Services An inclusive approach

By Hannah Shepherd

Introduction

At the **Thinktank** Science Museum in Birmingham, the staff deliver educational workshops to school groups, attempting to present aspects of science and history to all children including those with learning difficulties in a 'fun' and inspiring way, using objects and practical activities.

The purpose of assessment for museum education staff is to find out how the workshops provided and the practise of the education staff in the museum classroom affects the learning of pupils. Only if the museum is providing effective learning opportunities will students, and their teachers, continue to use the museum educational service.



Assessment of workshops should be primarily

influenced by the experiences of students taking part. By finding out what, why and how a child learns, teachers and other education staff can determine teaching approaches for creating effective learning opportunities (Clark & Leat, 1998). Recent legislation states that children should have the opportunity to be involved in the choices made about their education (DfES, 2001 3.6 pg. 28).

Assessment of the museum service tends to be summative, to record the achievement of a pupil, and leads towards an evaluation of the educational workshop being provided, specifically the subject content and the delivery techniques used.

Assessment of an educational workshop at Thinktank

Twelve students from a school local to the museum, all of who have some moderate difficulties in learning, attended a course that studied the subject of electricity. A formative assessment of the student's knowledge of the subject took place, where it was found that the majority of the students could indicate household items that used electricity. Most of the students were also aware that electricity could be dangerous. None of the students could demonstrate ideas about how electricity worked.

As the sessions progressed some changes were made to the proposed programme based on the responses of the pupils to the planned activities.

The major tool used for eliciting information from the students was group discussion, during which some students contributed more than others for several reasons, for example, some had communication skills that were more easily understood by the museum staff, some were more confident in expressing their opinions. Small task groups were used in each session giving individual students the chance to develop their understanding of the subject and allowed students the opportunity to progress at differing rates. Small task groups also allowed school and the museum staff to assess the individual students learning in more depth.

The final assessment for this programme was summative, it was explained to the students that their ideas about the programme would help the museum staff to improve the sessions.



Museum staff asked the following questions

- What did the student's enjoy / dislike about the sessions?
- What could the students recall of the session content?
- How would the students change the sessions for future participants?

A number of methods were used to enable the students recall the sessions including watching videos and looking at photographs of the sessions that recorded their learning experiences. Also, large cards that showed the skills that had been used, augmented by symbols and written word, were used to prompt students into recalling their learning experiences. The advantages of this method were:-

- Students worked together to identify learning outcomes
- Use of visual media enabled the students to recall sessions easily
- Discussion helped students to recognise their own learning as they recalled information acquired and skills used

The disadvantages of this method:-

- The opinions of some individuals were taken as the answer for the majority
- It was difficult for some students to recall activities from the earlier sessions of the programme
- Evidence was not always recorded absolutely
- Some of the learning outcomes may not have been identified because of the questioning techniques

There may be difficulties in accessing the views of children, but the interviewer has a responsibility to reflect those views as authentically as possible. (Lewis, 2002)

Children themselves, are the best source of information on their opinions and experiences, particularly concerning their education. While this is an issue that relates to all children it may be a specific consideration of communicating with children with learning difficulties, a traditionally marginalized group (Gwynn, 2004).

Research shows that assessment can lead to an improved workshop. Observation of students can lead to the identification of the needs of individuals within a



group and thereby better establish ways of facilitating learning and increasing the experience for each child (Tilstone, 1998). It is important to recognise that during observation of children, individual teachers, and others, such as museum staff, will interpret the behaviour of children differently. It is easy for the observer to be subjective about individual children based on previous experience (Tilstone, 1998).

From the assessment it was clear that the students could recall much of the programme content, which indicated that the methods used to demonstrate the subject had been effective for the learning experiences of many individuals. The programme was redeveloped following this assessment and was based on the students' opinion.

The nature of the education department at *Thinktank* Science Museum allows little time for assessment for the purposes of evaluation. Future delivery of a specific programme may not be assessed to the same depth with another group of students. It was therefore an opportunity for museum staff to learn from this assessment.

Classroom assessment techniques and the relevance for museum education settings

In eliciting the views of students with difficulties in learning, assessment of learning outcomes may rely on close observation of the individual by the practitioners that know that student



particularly well. (Aird, 2001) There is a conflict here between the benefits of having an unbiased view on the student responses to questions asked in the interview, while providing the best strategy for communication by that individual.

In a museum education setting there may be limited opportunity for staff to work with a specific group of students over an extended period of time due to the large numbers of pupils accessing the service. Museum staff may have difficulties in recognising the varied responses of individuals, particularly during a group interview, which would affect the data gathered for evaluation. Video recording may be one way of ensuring the true outcomes of the assessment can be recognised and provide a record that can be referred back to by museum staff.

The analysis of data gathered is also open to personal values and may be influenced by what the observer would like to see, therefore, the interpretation of an assessment should be shared with other staff (Clark & Leat, 1998).

Methods for eliciting the responses of students having difficulties in learning

In a museum education setting where students attend workshops there are many tools that may be used to support communication. The use of Augmentative Alternative Communication (AAC) may help many individuals within a group of students and not only those with learning difficulties. An example of AAC communication could be the use of objects in a workshop, which typifies museum education. This 'hands on' approach to teaching could provide positive learning opportunities for many students, not only those with learning difficulties, and inspire further learning (Bell, 2002).

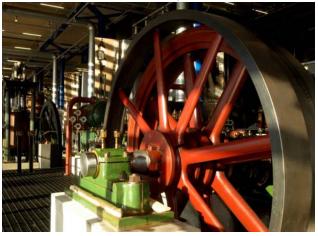
By generalising the responses of students when using communication other than verbal or by including opinions of the students view, the facilitator may relate an incorrect view from the student to the assessor. The use of symbols or pictures can support communication but the respondent is then limited by the choice of symbols or pictures the facilitator.

Gestures, movements and facial expressions may convey opinions, particularly if the respondent has little or no verbal communication skills.

In assessment carried out at Thinktank Science Museum, the education staff tries to establish the learning outcomes for pupils to improve the educational value of workshops. Assessment rarely becomes part of planning for the individual student in the museum setting; instead it has to feed into the planning of delivery techniques to students yet to take part in that workshop.

Moving forwards - recommendations for museum staff in classroom assessment In the move towards inclusion for all if the museum is to provide excellence in education it needs to listen to the audience.

The techniques used with pupils having difficulties in learning should influence the ways in which all of the educational services are assessed. By avoiding the use of leading questions, providing visual aids to support the recall of information and by giving students the opportunity to comment on their own learning experiences, museum staff can better find the impact of the education service and may overcome the bias present in an assessment.



Museum staff my have difficulties in accessing the views of students, particularly where communication strategies of individuals may be unfamiliar to staff. These difficulties can be counteracted by the use of a variety of augmentative communication techniques and the support of facilitators. During assessment, museum staff, and facilitators, may unwittingly interpret incorrect views of students (Lewis, 2002). By being aware of personal values and beliefs, by recognising that there may be a desired response or expected outcome, and by effective recording, the assessor may avoid



influencing the opinions of a student to some extent.

Communication is the key to evaluation through assessment. Museum staff should not only consider why it is necessary to gain student opinion of educational workshops, but how those opinions can be obtained.

For museum staff, gaining the opinions of students can influence future delivery by identifying the efficacy of the learning experience. While it may be unrealistic to assess each workshop delivered, museum staff can learn much from a single evaluation, particularly if the opinions are sought effectively and the outcomes of the assessment are shared.

Communication techniques used in assessment to access the views of students may also help museum staff to identify ways of delivering workshops in a more inclusive way. Through assessment, museum staff should recognise how they can create effective learning opportunities for students, including those with learning difficulties, and thereby ensure the viability of the education service provided.

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Audio Communication Support

for people with learning disabilities

By Anthony Chiari

This article highlights how the use of audio CD's in our work with people with a learning disability can assist the communication process for them on a range of important issues in their lives.

The initial idea for this service started about 18 months ago when I made a decision to reduce

my working hours from 5 to 4 days per week. This reduction in hours required me to consider all the work I was undertaking at the time and to try and prioritise this.

I have been working in Milton Keynes as a community nurse for people with a learning disability for many years and one of the pieces of work I was carrying out at the time was running two music groups. One session was run specifically for people with a profound and multiple learning disability (PMLD) and the second music group session was run for people with a challenging behaviour. I had been running these two groups on a weekly basis for some time with the support of staff from the respective residential areas. However, because of my workload with people in the community and the reduction in my working hours. I was no longer able to continue with the music sessions.

This presented me with a dilemma: I needed to stop running the music groups because of my other workload commitments but felt uncomfortable with bringing to a close something which was running successfully and that people were benefiting from. I needed to consider how best to cease my physical involvement with the music groups, at the same time as enabling the sessions to still continue without me.

This dilemma was resolved one weekend when I was working at home in my recording studio. I had been recording rock music for many years and so was versed in the use of the necessary technology for the production of this type of music. This

naturally led to me recording myself singing the complete music group sessions in my studio for <u>each</u> of the two groups (PMLD and challenging behaviour). These recordings were then subsequently produced and made into CDs. The CDs were also supported with a laminated running order of the songs within the sessions, with a brief overview of what each song was trying to promote (eye contact, fine motor skills, turn-taking, tolerance of others etc.).

The CDs and laminated instructions were presented to staff from the two residential areas. I worked closely with staff that were keen to take the facilitation and continuation of the music groups on board. This very quickly enabled the staff from the residential areas to acquire the confidence to be able to continue running the music groups on a weekly basis without me being present. I was very pleased that the music sessions did not have to cease because of my reduction in hours and the necessary prioritisation of workload.

This whole process, and the relative ease that it took me to produce these CDs, led me to think about how I could use CDs in other ways to facilitate and reinforce our communicative involvement with people with a learning disability.

I started looking at the opportunities that people with a learning disability, with whom we worked, were presented with in our team when confronted with the normal communication 'flow' of information through our services. I was interested in the extent to which these opportunities were truly relevant and meaningful.



The following are examples of common, written communication with people in our area:

- 1. The initial letter of contact with a person after a referral has been received.
- 2. The subsequent assessment that is then completed with both the person and their family/carers/professionals.
- 3. The health/teaching/care-plan that evolves after the assessment has been carried out.
- 4. The review that is then undertaken to discuss progress.

It became apparent that it would be possible for the person with a learning disability to receive the initial letter of contact in CD form so that they could 'hear' the letter and possibly 'see' the author of the letter as a picture or symbol on the CD. This could also be the case for the other three areas of traditionally 'written' communication.

The main benefit of this system is that it would have no disciplinary boundaries and different professionals would be able to use the CD format in different ways to enhance their work:

- An occupational therapist would be able to provide CD instructions on the use of a microwave for cooking a particular dish. Over time this may lead to a person being able to gather a collection of these CD 'recipes' so they may be able to exercise choice as to 'what to have for lunch' throughout the week.
- A psychologist would be able to provide recited techniques on how to alleviate anxiety, for example.
- Minutes of a persons' review meeting could also be recorded on CD with pictures on it of all the people that attended – a supporting document could also include a simplified, or symbol assisted, version of the key points of the review. In some cases the different sections of the review could include the actual voice of the person that the

section pertains to (social worker, parent, teacher). This could help the reviews to become more personal and meaningful.

- People living on their own, who have limited communication, could have their own CD that gives visiting support workers/carers instructions, or advice, on personal preferences, medication regimes and timings for personal/social activities. This system could promote a and consistency reassurance of the person, approach to across agencies.
- A doctor/psychiatrist and supporting staff would be able to provide audio guidance on the type, timing and taking of medication.

Also the very nature of the CDs, and the reinforcement and guidance/instructions inherent in the recordings, could ensure that they provide prompts on the important issues of a person's life throughout the day or at times when carers/professionals where not always able to be physically present with the person.

Another way that these audio CDs could be used could be as part of a marketing strategy for a service: either for general marketing purposes or for them to be distributed to job applicants or to out of county services interested in the services in ones area. The CD could have recited information about the service, or job, with pictures of the key service members on it. This would make the information more personal, accessible and 'human'.

I feel that the uses for this system are potentially endless and could be implemented for the benefit of people with a learning disability regardless of the agency that is involved, whether it be health, social services, teaching or private sector.

However, where the potential uses of this system are endless the recording and production of these CD's falls into two distinct categories:



- 1. Ordinary applications: This is where I foresee the majority of demand to lay. It is where the voice heard on the CD does not have to be that of a significant person. This would involve my voice being used to recite the agreed careplan, instruction or review minutes. I would carry this out after I had received a phone call, letter or e-mail detailing the exact words/guidance of what it was that needed to be recorded. Provision of necessary pictures (usually in .jpeg format) or symbols would be required if it were considered important for these to be included on the body of the CD.
- 2. Voice critical applications: This is where the voice heard on the CD is essential in aiding the communication process for the person with a learning disability. This may need to be the person's key-worker, class teacher or social worker or another familiar person. The decision for this method would need to be made by those working closely with the person and would require me to visit the area to record the key-worker reciting the care-plan, instruction or review minutes.

I have had a meeting with my manager recently proposing the adoption of this idea within the Milton Keynes area. We have agreed that I will undertake to work closely with a variety of staff and disciplines within the team so that they can sample this 'CD assisted aid to communication' with a person they are working with currently. I will provide this service free to Milton Keynes initially and will then meet again with my manager to review how this service has

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Tel: 01277 365626, Fax: 01277 365003 Email: lucy@theatre-resource.org.uk, Website: www.theatre-resource.org.uk actually benefited the people that staff have been working with.

Many people, both past and present, have provided me with a critical overview of the various stages that my thinking and ideas have gone through to enable me to get to this stage today. I would like to express special thanks to Ann Fergusson (University College Northampton) and Rob Lee (Greater Peterborough Primary Care Partnership) for the advice and expertise they offered me in the development of this service. I would also like to thank Mark Prescott (Integrated Services, Milton Keynes) for his encouragement and willingness to trial the service in Milton Keynes.

Recently a member of staff, from one of the residential areas where I had been running one of the music groups, said to me that even that even though she had not seen me for many months she found it annoying that she could still hear me on a weekly basis!

I have taken this as a mark of success that the CD's have had in one area.



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Inclusive approaches

Website to promote social inclusion A website run by John Parry to promote social inclusion will welcome contributions on a wide range of topics from people with and without disabilities.

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How music can increase the responses for pupils with PMLD

by Lynn Hammersley

Introduction:

I recently completed a dissertation for a M.Ed. in Learning Disabilities at Birmingham University; the topic focused upon whether an introduced music scheme provided suitable activities to increase responses in pupils with PMLD. I undertook the course since I was new to teaching pupils with complex needs, although I had been teaching in mainstream primary schools for 23 years.

Why Music?

The literature review necessary for my dissertation was very enlightening. It was also gratifying to find so much research supporting my belief that music is an integral part of being human. I have always been extremely involved in a wide range of musical activities and can appreciate how uplifting and rewarding music can be, both in performing and in listening. During my teaching career I have noted that music can enhance pupils creativity, provide an outlet for emotions and be very effective in raising self-esteem. Before undertaking the research I had noted that many pupils with special educational needs react to music. For example, a pupil with autism communicated with me because he wanted access to a large orchestral gong. This was the first time he had reacted in this way, taking hold of my hand, putting in onto the cupboard door handle and taking me to the instrument he desired. Another pupil with PMLD showed a marked increase in foot movements (the pupils' only limb that was controllable) during music lessons involving singing.

In exploring other research I found many examples that supported my hypothesis on the importance of music. Nordoff and Robbins (1975) quote Plato, stating that "...music is a moral law. It gives soul to the universe, wings to the mind, flight to the imagination, a charm to sadness and a life to everything" (intro). Bunt (1995) suggests that music has been used throughout history as a "healing force" to alleviate illness and distress although it is only in more recent times that that idea of music therapy has developed specifically for this function.

Storr's "Music and the Mind" (1992) is an excellent book which helps to explore how useful music can be. Storr suggests that music can penetrate the core of our physical being, can make us weep, can simulate being in love and transform the quality of our whole existence. Storr suggests it is natural for us all to crave excitement in our lives and that music can fulfil this desire. He states that the arousal music can produce in an individual can be measured scientifically by monitoring brain waves, eye dilation, electrical resistance on the skin, respiratory rate changes, heart beat and blood pressure changes. Alvin (1965) also found that for certain pupils with a psychotic conditioned or those with cerebral palsy, the pentatonic scale had a sedative effect on them. Savan (1996) found that certain music (by Mozart and Bach) had a calming effect on pupils with behavioural problems and suggested that the music affects their adrenalin and corticosteroid levels.

Juslin and Sloboda (2002) state that "...mothers' speaking was not as engaging as their singing" (p.114). This suggests that babies need the interaction of their mothers through song to stimulate their growth. Mortimer (2000) also comments that music is an amazing thing for children. "It encourages children who find it hard to move, to move more freely." He states that it can calm a new born baby, capture a toddler's attention and give the opportunity to join in a social activity when normally the child would be too young. All these ideas support my long term belief that music is a fundamental part of education and can open up new ways of communication and allowing pupils to explore new ways of



expression and movement, and in the case of pupils with PMLD, can stimulate more responses and bring a creative element into their lives

Research Project:

I chose to pursue a research project involving music since this was my coordination subject responsibility in my school. Although I had taught music to mainstream pupils, trying to understand suitable strategies that would work for pupils with severe learning difficulties was a new challenge. I had been on various courses and had found a very useful book,' Access to Communication Through Music' by Margaret Corke (2002). It contained many practical activities suitable for pupils with PMLD or complex needs, and I incorporated these ideas into a set of lessons for my research project .The small scale research project lasted for 5 sessions and focused on how one pupil responded to the musical activities offered. I videoed the pupil for a limited period: 1 minute at the beginning and end of the session (taking part in a familiar activity) and 2 minutes in the middle of the session when a new activity was introduced. Each session was carefully recorded in order to show the position of the pupils and the camera, the involvement of staff and any interruptions to the lesson were also noted.

The pupils responses recorded were:

- Ÿ eye movements blinking
- Ÿ body movements head / hand / fingers
- Ÿ facial expressions smiling / frowning / crying
- Ÿ vocalisations as suggested by Hopkins (2002)

Each session began by positioning the pupils in a circle and giving each a sleigh bell as an object of reference (to tune them into the activity) whilst other pupils could be positioned. The sessions lasted approximately 30 minutes and three members of staff were present. However, as with all practical research projects, the session did not always occur as planned due, for example to interruptions or pupil and staff absences. The songs and activities used were selected from Corke's

(2002) book and are listed below. Each worked very well with the pupils in the group.

- Ÿ "Hello, Everyone" general introductory song using each pupil's name
- Ÿ "Rainmaker" using a large rainmaker instrument and allowing the pupils to feel the vibrations
- Ÿ "Time to have some fun today" a peeka-boo game song using a silky scarf to 'hide' the pupils and encourage them to pull the scarf off their heads
- "Ocean Drum" using an ocean drum to encourage the pupils to look up over their heads and also feel and play where possible
- Ÿ "Hooter" use a 'car horn' as a novelty instrument
- Ÿ "Dingle Dangle Scarecrow" simplified version with clothes and hats as props
- Ÿ "Goodbye Song" last song to calm them down and give cue to end of session

Margaret Corke also suggested that staff should create their own songs. Since it was Autumn we made up a song using leaves and an electric fan called "Lots of little leaves" (an adaptation of a song found in 'This Little Puffin' (1977).

Results

The responses recorded from the first three weeks showed a steady increase in the pupil's responses but a levelling out in week 4. The fourth week did, however, show a marked increase in hand and finger movements and also the pupil actually lifted his head which was unusual for him. Unfortunately in the last weeks of the project, building work caused a major disruption to the lessons and all pupils were also badly affected by the noise generated. The results reflected these difficulties.

Some significant responses occurred in week three when the pupil smiled in response to the noise of the motor horn. Such a response could be interpreted as showing pleasure, as suggested by Storr (2000), in that people need stimuli in order to feel more human. The timbre of the instrument may have been the reason for the response (Bunt 1994). On the other



hand the pupil may have become more used to the repeated activity. Corke (2000) suggests that by using repetition the learner feels more secure and is more willing to interact.

Conclusions

I can conclude that in this study the music activities presented to the pupils did increase involvement and responses. Music can indeed 'reach the parts other subjects can not', and it can penetrate and stimulate where other subjects may not be able to, since music can be felt through vibrations and heard through sounds.

Singing to pupils also produced encouraging responses and I would like to

encourage all members of staff to turn off the tape-recorder and use their own voice to sing to their pupils, as a mother would sing to their infant. Simple repetitive songs and interesting objects can capture the attention of pupils with PMLD and novelty can give the opportunity to a surprise response. I know through past experiences that music is the one subject that staff feel the least confident about.

Perhaps Margaret Corke's book will inspire you as it did me. I hope you and your pupils get as much pleasure out of your musical activities, as my pupils and I are continuing to do.

Lynn Hammersley

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Rock-a-bye-blues: Music as a tool for parents By Nick Logan

The role of music in intervention for children with, or at risk for, profound and multiple learning difficulties is not only becoming more appreciated, but more sophisticated in its application. The understanding that music by-passes, supersedes or substitutes for more cerebral forms of contact and communication between people has been known for centuries, but its therapeutic capacities are only now beginning to be fully appreciated by the clinical communities.



There is no culture in the world that does not involve some form of music as a medium of intuitive expression. Music may perhaps have preceded language in our human need to communicate and seek comfort for stressed minds and bodies. Music can calm deregulated physiological systems; can improve sensory integration; can act as a carrier of learning; can facilitate connection between individuals; and give a sense of well-being and joy (Berger 2002).

Julie Wylie, music specialist at the Champion Centre in Christchurch, New Zealand has for many years been using music with a wide range of children, including those with Downs syndrome, those born prematurely and those with a wide range of difficulties that makes them difficult to soothe as infants. Those born extremely prematurely are of particular interest to Julie and have been the impetus for a research project and a new collection of songs and music designed specifically for this, and similarly fragile, populations whose early months are characterized by long stays in hospital, and whose difficulties often remain throughout the preschool period and beyond.

Premature infants' responsiveness to social stimulation prior to normal birth age remains largely unexamined. However, there is evidence that parents of sick premature babies show less face-to-face contact, smiling, affectionate touching and talk in their interactions (Wyly 1995), and that some of this can be improved through the use of music. Trevarthen (2002) suggests that parents be allowed to sing and chat to their babies in loving ways, even when they are in the neonatal intensive care unit, because the musical qualities of the parents' voices can be, and are, responded to by even very premature children.

Living with an infant in intensive care, often not knowing whether the child will 'make it' or not, is enormously stressful for parents. The sense of powerlessness it induces in parents can be overwhelming. As the mother of India Neville, born at 24 weeks said:

My husband and I felt as if we were on a different planet where everyone but us knew what to do for our baby. Music seemed the only way of creating a safe, intimate environment where I could truly become connected with my little girl.

Singing with her hand on her baby, made this mother feel a sense of safety and security for herself and her child, and helped both parents establish a means of becoming emotionally and physically connected to their tiny infant. In research into these early connections, Steven Malloch has shown that premature infants do indeed respond to such 'musical companionship'.



He says, 'Even such an immature human has a complex sense of timing of vocal expression comparable with that of adult expression, and their ability to exchange coos in alternation with the parent is similar to the rhythmic patterns shown by infants in spontaneous vocalizations weeks and months after full-term (Malloch, 1999).

Research is increasingly reinforcing the clinical observations that children throughout the preschool period, who were born prematurely (usually at 28 weeks gestation or less, and weighing as little as 450 grams) have problems of physiological regulation that make concentration sporadic and distractibility a common concern. Their body rhythms are uneven, making coordinated movement such as jumping and hopping difficult. And they often 'flit', finding it difficult to stay in reciprocal exchanges with others. All these concerns form the focus of musical intervention at the Champion Centre, and in a piece of observational research across a six-month span, Julie Wylie documented emerging physical and social coordination through



song, musical story-telling, action rhymes and rhythms, and musical play. Children and parents emerged with a wider repertoire of musical ways to be with each other, a greater capacity to play, and a much greater joy in being with each other.

Following the research, and as a culmination of work Julie has been doing for decades, she and an international group of musicians and music therapists have produced a CD for parents entitled "Rock-a-by Blues". It comes with a book of songs and musical arrangements, and is ideal for the musical and the non-musical parent alike.

The purpose of the collection, produced in collaboration with Dr. Beth Bolton from Temple University (USA) and Beth Rankin from La Trobe University (Australia), is to provide an eclectic range of music that helps parents and caregivers to develop confidence to use music to comfort and support themselves and their child/children and to interact playfully and musically. Parents can identify with the words and emotions expressed through the range of songs and music. Babies and young children can respond to the sounds of other babies and young children.

The recording contains several songs specially written by parents for their infants. India (the little girl mentioned above) is one of the child singers on the CD. At the time of the recording, India was four years old. She sings with a playful delight that reflects the important role music has played in her life from the very beginning. Another song was written by a parent for her child with Down syndrome. The whole CD is intended to develop a parent and child's listening and interaction vocabulary in music with songs and lullabies from around the world.

Music presents one of the most viable resources for putting the body at ease. It can calm it down, letting the brain and the sensory systems relax and enjoy the incoming flow of sensations. Music can open the brain to learning. This is why it is an important part of the early intervention programmes of all children at the Champion Centre, and can be of value for all those with complex developmental delays.

Musical play celebrates childhood and helps parents and caregivers of children with a range of physical, intellectual and emotional challenges to enjoy moving, pleasurable, reciprocal play. It promotes healthy parent/child attachment and interaction. The more we sing, chant, move and dance with our children, the more involved and responsive the child will become in music making and learning. Music can arouse or calm. It can regulate stressed systems of both parent



and child. It has the power to inspire, delight, transform and motivate. It can touch the soul and bring healing to the singer and the listener.

The last word goes to a parent of a child with Rett's syndrome, and comes from an earlier publication by Julie (Wylie, 1996):

Antoinette is four and a half years old and has Rett syndrome. She is the youngest of our four children. Music plays a big part in Antoinette's life as a therapeutic aid. She loves catchy tunes and, although she has limited use of her legs, her feet move in time with the music. It is amazing how the right music can transform her from screaming to laughter in a matter of seconds. Music and singing along also make it much easier to perform many activities, particularly her Physio exercise, which otherwise is a real chore. Antoinette has become a lot more relaxed and very vocal since she has had a music specialist working with her at daycare and also a session at Early Intervention once a week. Julie holds her hands and has Antoinette dancing around the room, when normally she can barely walk. Julie has also successfully encouraged her to attempt various instruments, such as beating a drum, despite her finding it almost impossible to grasp anything in her hands. We gave Antoinette a Playskool animal keyboard for Christmas. She adores it, and her face lights up with pleasure when we turn it on. She has learnt to hit the keys herself to produce various animal sounds, and, for a little girl who has no speech and is virtually unable to use her hands and feet, this apparently small feat is a huge accomplishment.

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Copies of the CD "Rock-a-bye-blues" can be ordered from Clare Tatterson, Developmental psychologist, Sunfield, Clent, Stourbridge, Worcs (Tel: 01562 882253) at a cost of £10 including postage & packing within the UK.

More information about the Champion Centre music therapy programme can be received from Julie Wylie. General requests for information about the Champion Centre should be addressed to the Director, Dr. Susan Foster-Cohen, The Champion Centre, Private Bag 4708, C/- Burwood Hospital, Christchurch, New Zealand. (e-mail: susan@championcentre.org.nz)





European Agency for Development in Special Needs Education

By Amanda Watkins

The European Agency is an independent, self-governing agency established by the Ministries of Education in member countries to act as a platform for collaboration in the field of special needs education. We are maintained by 23 Ministries of Education in the participating countries - from Summer 2004 these are the 19 EU countries, Iceland, Norway and Switzerland, with Cyprus and Poland participating as observers of the Agency's work. In addition, we are also supported both politically and financially by the European Union Institutions (European Commission and European Parliament).

We offer our member countries a unique opportunity to exchange knowledge and experience in such a way that quality in special needs education provision is promoted. Member countries can learn from each other by drawing upon our ability to provide different types of real-time and virtual opportunities for exchanging knowledge and understanding.

Aims and Objectives

All aspects of special needs are considered within the scope of our work, as our ultimate aim is to improve educational policy and practice for all learners with special educational needs. This aim takes into account issues such as equal opportunities, accessibility, inclusive education and the promotion of quality of education, whilst recognising that there are differences in countries' policies, practices and educational contexts.

One key objective for us is to provide an effective system for the collection, processing and distribution of information regarding new and innovative measures in all areas of special needs education, as well as by focusing on subjects of high priority for the further development of special needs education. These subjects are identified by our Agency member countries and are always considered in such a way as to promote a broad concept of "special needs"

education" within a framework of high quality of education for everyone.

Target Audience

The main target groups for our work are the policy makers, experts and professionals who influence policy and practice in special needs education. As well as being able to use the Agency as a European knowledge centre, these target groups in member countries are able to call on us as an organisation that facilitates the process of professional learning and development through various forms of exchange of information and experience.

Member countries' involvement in the our project work and the development of various information products and outputs related to projects is as beneficial to them as being able to apply in practice the varied outcomes which they get access to.

Our Organisational Structure

We have a distinctive structure. This is firstly because of the people involved in the European Agency - National representatives nominated by the Ministries of education in each of the member countries from the policy (Representative Board members) and practitioner levels (National Co-ordinators) who share a common understanding of key issues in special needs education and who work together to provide authoritative perspectives on special needs education in their country.



Secondly, these National representatives work together with the Agency staff to develop a common understanding of key issues at the European level.

Useful Information Resources

The information we process is distributed by means of our newsletter *EuroNews* as well as publications and reports. All of these publications are translated into our 17 working languages and are available free of change as downloads from our website: www.european-agency.org

We also organise seminars, conferences, events and reports and commentaries from these are also available from the web site.

On our website you will also find topic databases as well as specific web information services and National Pages of country specific information for each of our member countries. In the Contacts section of the National Pages, there are listings of key support organisations dealing with particular special needs and disabilities.

If readers have specific questions about situations regarding particular special needs policy or practice in our member countries, then as well as consulting the website, they can contact the National Co-ordinators of that country - all of their contact details are on the website.

More information from the European Agency

If you would like more general information about us, the first place to check is our website www.european-agency.org

Specific questions can usually be dealt with through our Secretariat in Denmark

European Agency for Development in Special Needs Education Teglgaardsparken 100 DK-5500 Middelfart

Denmark

Phone: +45 64 41 00 20 Fax: +45 64 41 23 03 adm@european-agency.org

Or through our Brussels Office

European Agency Brussels Office

Avenue Palmerston 3
B - Brussels 1000 Belgium
Phone: +32 (0)22 80 33 59
Fax: +32 (0)22 80 17 88
brussels.office@european-

agency.org

Amanda Watkins
Information Dissemination Manager
amanda@european-agency.org

Legislation

Draft Mental Capacity Bill - People First "Bad Law Alert"

People First, a nationwide self advocacy movement among people who have learning disabilities, and the Coalition of Organisations of Disabled People are campaigning together to voice their objections to the draft bill. Campaign details and materials are available from the national office.

Contact: National People First, 299 Kentish Town Road, London NW5 2TJ

Tel: 020 7485 6660,

Email: campaigriing@peoplefirstltd.com

Website: www.peoplefirstltd.com

NEW Section to PMLD Link

RESEARCH

Unit for Development in Intellectual Disability (UDID)

By Coral Seal

UDID is based at the School of Care Sciences, University of Glamorgan and brings together university based staff and staff from the Special Projects Team (Bro Morgannwg NHS Trust). Its' aim is to enhance quality of life and quality of service provision for people with a learning disability and their families and carers via an integrated programme of research, education and practice development.

Partnership is central to achieving our aims. Our work is informed by three advisory groups – TRAC (an advisory group of people with learning disability), a parent/carer group, and a multi-agency practitioner group. UDID also has a network of links both nationally and internationally.

Over the coming year we will be commencing new research studies, developing new courses and workshops, and working with service providers to facilitate service development. We will also be developing a programme of seminars and conferences (see News and Events section in PMLD Link).

A membership scheme has been launched. This is open to both individuals and organisations – in fact anyone with an interest in promoting quality of life and quality of service provision for people with learning disabilities and their families/carers.

For further information please contact: Coral Seal, Project Manager, UDID Tel: 01443 483192: email: cseal@glam.ac.uk Website: www.glam.ac.uk/socs/research/UDID

Assessing the Health and Social Needs of people with a Learning Disability By Clair Cairn

Brodie Paterson (Senior Researcher) and myself (Clair Cairn – Research Assistant) work for the University of Stirling and have been commissioned to



carry out a Service Development Project in relation to the Health and Social Needs of people with a Learning Disability. The project will be focussed at a Local Level – the Forth Valley area, in Central Scotland.

The project was commissioned by the NHS Health Board in Scotland, the three Councils within Forth Valley. Its intention is to develop and support the planning of future services for individuals with a Learning Disability, to successfully meet both their Health and Social Needs. Epidemiological work will be carried out with all those individuals who have a Learning Disability and who are known to services. Children will also be included in the epidemiological work, but only adults will be involved in the more indepth assessment. A sub-sample will be taken from the larger sample, which will represent various demographic variables and different forms of Learning Disability. There will also be a particular focus upon five areas, which are perceived to require further assessment in this Local Area:

- Profound and Multiple Disabilities
- Autistic Spectrum Disorder
- Challenging Behaviour
- Mental Health
- Elderly

It is intended that we will use general measures of Quality of Life and Health Needs, assessment tools more specific to the individual's diagnosis, functional capacity measures and satisfaction measures, as well as, semi-structured interviews to try and discover exactly what is needed by each individual, in terms of Health and Social Care. It will also aim to determine whether these needs are being met and what their options are at the present time. The semi-structured interviews will give each person an opportunity to express their own opinion, whether positive or negative.

We are currently looking for Health or Social measures / assessment tools, which people are aware of, that have been used for those individuals who have Profound and Multiple Disabilities or if there are currently other measures available or in use at present.

We would really appreciate any information or response to the above. Many thanks.

Contact details needed



Call for Evidence: Health and Education

If you work in an area that is developing good creative and flexible working practice to ensure that children with complex health needs can fully access schooling we would like to hear from you.

Health Needs in Education is a one—year project set up to develop materials to be used in schools and early years settings which highlight good practice that supports children with complex health needs in these settings. By complex health needs we will be including children who require co—ordinated assistance in order to maintain optimum health during the school day — this may involve assistance with enteral feeding, catheterisation, using ventilation or requiring emergency treatment such as rectal diazepam or buccal Midazolam.

This project is funded by the Department for Education and managed by the Council for Disabled Children. The work is supported by the Health Needs in Education Consortium which embraces a range of organisations, including Mencap, BACCH, the DRC, and the Royal College of Nursing.

We do not intend to reinvent the wheel; we would like to bring together examples of good practice which exist around the country. If you have been part of developing or maintaining a protocol in your local area, or have a case study that highlights good practice please could you contact Jeanne Carlin at jeanne@jcarlin.karoo.co.uk

To contribute to this discussion reply by e—mail to pmldnetwork@ldforums.org (subject: Call for Evidence: Health and Education). To start a new topic, please reply using a new subject heading. To view, or reply to this message on the forum website and to see previous messages in this discussion, please visit: http://www.ldforums.org/Webx?50@@.2cc18755

This Forum is brought to you by the Foundation for People with Learning Disabilities http://www.learningdisabilities.org.uk

To join a forum please visit:

http://www.Learningdisabilities.org.uk/page.cfm?pagecode=AUFO

To unsubscribe from this discussion go to:

http://www.ldforums.org/WebX?280@@.2cc18755!folder=.1dcf5463

The editor of the next PMLD LINK is **Beverly Dawkins**

'Communication'

The copy date for all articles, information and news for the Spring issue is the 4th February 2005 and the focus is on 'Communication'.

Don't forget to send all contributions to Beverley Dawkins preferably in RTF (Rich Text Format) or 'Microsoft Word' Beverly's contact details are on page 2). If you are also able to supply photographs and/or images to enhance your article please do so, but it is important that the relevant permission to publish is obtained beforehand.





Early intervention: shaping the future

By Lesley Campbell

"Early intervention can maximise the life chances and improve the quality of life of children and their families"

National Service Framework for Children 2004

"Early intervention is the cornerstone of our strategy..... It is vital that early identification is followed up by efficient early intervention so that parents can be confident that once problems are identified help will be forthcoming"

Removing Barriers to Achievement DfES.2004

Background to the feasibility study

There is an emerging focus on early intervention in the UK with the National Service Framework (NSF) for Children having early intervention as one of the key messages.

The DfES strategy for SEN 'Removing Barriers to Achievement' includes the feasibility study to set up a National Centre for Early Intervention. Mencap is leading this project which reports to the DfES in March 2005. Through the feasibility study we are building an alliance of parents, practitioners and organisations that want to see very much more focus on early intervention in the UK.

Early intervention has recently become something of a buzzword, meaning very different things to people in different contexts. In this feasibility study we are following international thinking and define early intervention broadly as 'any activity designed to promote the learning and development of young disabled children'. The focus of the feasibility study is on disabled children from birth to five years and covers children with every type of impairment.

The changing population of disabled children

There are many changes in the population of disabled children that provide the imperative for focussing on early intervention:

- Improved survival rates of very low birth weight babies
- Improved survival rates for babies with profound and multiple learning disabilities
- The roll out of UNHS (Universal National Hearing Screening) for babies is predicted to produce a 50% increase in the number of deaf babies identified in the neonate phase, with a significant proportion of these babies having additional impairments
- Increases in the diagnosis of children with ASD and ADHD
- Evidence of increased prevalence of disabilities within black and minority ethnic communities

[&]quot;From my experience the right support can make a huge impact" Parent



Why early intervention is important for children with profound and multiple disabilities. We know very little in the UK about which children with PMLD are able to access which early interventions, at what level of intensity or to what effect. Although many planners and commissioners of services have stated that babies with profound impairments identified at or soon after birth are followed up and offered a range of therapies, there is very little evidence to support this view. In fact for children with some life-limiting conditions there is anecdotal evidence of a 'wait and see' approach.

The context for a National Centre for Early Intervention

There is a growing recognition that for disabled children a postcode lottery exists for early intervention with many children and families missing out completely on the very early support that would make a difference. It is, for example, still not the case that Portage or home-visiting services are universally available to disabled children and their families. For too many children early intervention is not early enough with crucial months or even years missed. For other children, precious time and resources are wasted on interventions that are ineffective.

There are of course pockets of excellent practice around the country, in both special schools and specialist centres as well as mainstream services. However, the evidence base for early intervention for disabled children is weak. Even when early interventions have been evaluated these messages from research are not effectively disseminated. For both parents and practitioners it is a struggle to find out which early interventions work with which children and how to be trained to deliver these interventions.

"Many disabled children have been missing out for too long on the early interventions that would improve their life chances. The National Centre would be a great help to parents and practitioners in accessing the latest research on what works in early intervention" *Paul Ennals, Chief Executive, National Children's Bureau*

Shaping the future

The feasibility study is your chance to shape the future of early intervention for disabled children. We need to hear your views on making this work. There is a discussion forum and a lot of information the website. So, please take a look at www.earlyintervention.org.uk or email us at info@earlyintervention.org.uk or call us on 020 7696 5504

Lesley Campbell

Bag Books

Story-packs designed for children, young people and adults who are at an early developmental stage in the acquisition of language and communication skills. Each page of the story is a strong board with an object attached, which can be explored by each person listening to the multisensory story. Many titles are suitable for teenagers and adults.

60 Walham Grove, Fuiham, London SW6IQR

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REVIEW

Plymouth Recording and Assessment

By Rob Ashdown

Overview

This excellent assessment suite was written during 2001-03, by the Plymouth BARE Group. They are teachers who were funded to work together to produce curriculum guidance for pupils working at levels Below Age-Related Expectations (i.e. BARE).

The assessment suite is based on Access 2000 software, but the design is copyrighted by Plymouth LEA. Schools do not have to have Access installed to run the software. It can serve as a very useful model for schools and LEAs to develop their own package or, sensibly, they might adopt it unchanged. It has an easy-to-use help index which provides a good user guide to making full use of the assessment package and trouble shooting. Teachers will require support and practice to use the software with ease but it has the potential to cut down on the administrative burden of report writing and target setting. Head Teachers will want to know that information about pupils can easily be imported from other management software, again reducing effort. The next version, coming soon, will also allow users to export pupil data to other assessment programmes such as Pupil Achievement Tracker.

The assessment suite has a number of positive aspects: for instance, the software allows for school target setting by Key Stages; it allows selection of records by class group, year group, pupil or all pupils; it generates a curriculum profile map for each child allowing detailed overview of current attainment and achievements; there is opportunity to record comments and keep records for the future; and formats for reports and IEPs (individual education plans) are included and can be customised. It also allows pupils' progress through subjects to be seen on one table as well as comparing pupils' progress in groups in a single subject.

Head Teachers will want to seek their LEA's own view about its robustness and utility for school target setting. However, it easily

allows the generation of numbers and percentages of pupils predicted to attain particular levels at the end of each Key Stage, using information that the software installs in a PC. The assessment suite was developed initially as a 'standalone' program, but a networked version of the software will be available from January 2005.

In the case of their own school, users may wish to use the assessment suite alongside existing school assessment materials because no single assessment package can meet all needs. However, it is user-friendly and a labour-saving job aid for making objective assessments, for record keeping and reporting to parents, and for creating realistic and appropriate IEPs.

The assessment suite utilises recommended QCA assessment materials:

- > Foundation Stage Profile
- Stepping Stones
- Developing Skills
- P-Levels
- NC-Levels

Foundation Stage Profile – The level descriptions from the DfES Foundation Stage Profile are written as statements. The writers give examples of what children might be doing for each statement. Items 1 to 3 of the Profile in each curriculum area are the ones that are most relevant to children with SLD/PMLD. The examples include some reference to different communication media used by children, but teachers will know that the DfES Profile does not really provide the fine-grained developmental sequence to show progress of most young children with SLD/PMLD over two years. The software



allows any information entered on a pupil to be seen on an overall profile map and will print directly onto a template of the profile itself

Stepping Stones – Rather more detail is provided by the DfES *Stepping Stones* leading to the Early Learning Goals. Again, there are examples of activities and behaviours for the various statements. Most are relevant to children with MLD/SLD, but relatively few are relevant to children with PMLD. Where statements are very similar these have been linked to P scale references. Again, the Stepping Stones do not give enough detail to show progress of many young children with SLD/PMLD over two years.

Developing Skills – This part of the assessment suite covers generally agreed key skills that are fundamental to learning: fine motor skills - hand grip/pencil control, hand actions/manipulation, paper skills, ICT skills; personal care skills dressing/undressing, eating and drinking, personal hygiene, basic safety; study and organisation skills - attending to and directing attention, taking responsibility for independent working, understanding and evaluating tasks, recognising own needs and target setting. The indicators are relevant to pupils with MLD/SLD/PMLD. These will be complimented by a speech and language section in the future. P-Levels –The P-scales provide level descriptions covering all NC (National Curriculum) subjects, PSHE and RE, that have been designed explicitly for recording the progress of children with complex learning difficulties at Key Stages 1 to 4.

each P level. These items are most relevant to pupils with SLD/PMLD.

National Curriculum Levels – The same treatment is applied to the NC levels 1 to 5 covering all NC subjects, Citizenship, PSHE and RE. There are examples of pupil achievements for Levels 1-3, to make assessment at these levels more accurate. The statements are more relevant to pupils with MLD.

Conclusion

If you have not seen this assessment suite, it well worth investigating to form your own opinions. An impressive amount of effort and organisation has gone into producing a job aid for busy teachers to reduce the burden of planning, assessment, recording and reporting. Readers will want the support of their LEA in evaluating this assessment suite before adopting it and before committing resources to implementation. However, it should be a boon to teachers and it is so good that the Plymouth BARE Group have been committed to sharing their work with others.

The software is free of charge to schools and other education providers. For more information, log on to the Plymouth Grid for Learning (http://www.pgfl.plymouth.gov.uk).

Rob Ashdown, Headteacher....? School

Spiritual & Religious Needs of People with Learning Disabilities Seminar



The speakers the seminar on meeting the spiritual and religious needs of people with learning disabilities, held in London. From left: Peter Oakes (Adviser on spirituality to the Valuing People Support Team), Hazel Morgan (Co-Director of the Foundation for People with Learning Disabilities), Prof Chris Hatton (University of Lancaster), Andrew McCulloch (Chief Executive of the Foundation for People with Learning Disabilities), Prof John Swinton (University of Aberdeen), and Pat Charlesworth (self-advocate).



NEWS, PUBLICATIONS AND RESOURCES AfterLife

A new film starring an actress with Downs syndrome has been met with critical acclaim. 'AfterLife' opens 13 August at selected cinemas.

The film centres on a small Scottish family whose relationship is tested as they face changing priorities and challenging decisions.

Kenny is an investigative journalist on the verge of a major promotion who is forced to reassess his priorities when he finds out his mother is terminally ill with cancer.

Kenny's mother, May, is concerned about who will look after her daughter, Roberta, who is a bright, quick-witted and artistic girl with Down's syndrome. Will Kenny stay in Glasgow to chase his career, or will he return to the family's small-town home to look after his sister?

CONGRATULATIONS to the Centre for Special Needs Education & Research, University College Northampton

On Friday 29th October, the Centre for Special Needs Education and Research (CeSNER) hosted the Journal for Research in Special Educational Needs (JORSEN) invitation Research Seminar at Sunley Management Centre.

This prestigious event, sponsored by Blackwells Publishing, brings together 10 of the leading UK and Republic of Ireland researchers to share their current work in the field of Inclusive Education. This is the first time that this event has been held at UCN and provided an opportunity for post-graduate students within the School of Education to hear presentations from colleagues from Institutions including University of Manchester, Trinity College Dublin, Warwick University, University of Belfast and also Chris Derrington from CeSNER.

Roberta is played by Scottish actress Paula Sage who makes an impressive big-screen debut in 'AfterLife'. Also involved in Scotland's Special Olympics netball team, Sage shines on screen.

Lloyd Page, who has a learning disability, was impressed by the film. He said: "I enjoyed this film very much. I urge members of the public to go and see this film. It might change their attitudes."

To find out more go to: http://www.mencap.org.uk/html/news/news.asp

Card offers peace of mind to family carers

A new scheme to ease the concerns of families who care for people with a learning disability at home has been launched by Mencap.

The carers' card - described as 'A little piece of cardboard, for a lot of peace of mind' — wilt carry details of two people who have agreed to be a contact should the carer become ill or have an accident.

This will make sure the right information gets to the right people if a carer is temporarily out of action.

The carers card was launched in Surrey by Mencap's president, Lord Rix, earlier this month. If it proves successful, the card will then be promoted nationwide.

6 out of 10 people with a severe learning disability are cared for at home by family carers.

Speaking at the launch, Lord Rix said: 'Caring for a person with a learning disability is a great responsibility.

"I welcome this new caret-s card which I hope will ease the worries of parents and carers, giving them peace of mind for the future."

To get your free carers' card call the Learning Disability Helpline on 0808 808 1111.





Author: RNIB E&E

Publisher: RNIB E&E

ISBN: 1858781418

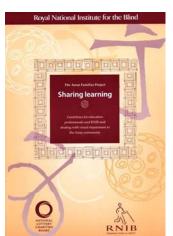
Pub Date: 1998

Price: £15.00

There's never an end to learning

In three programmes, the video sets out how the Teaching Assistant is involved in the assessment and development of residual vision, structuring and planning of the school day and in enabling children to live as independently as possible.

Video is 94 mins long. Video (PAL Video)



Author: RNIB E&E

Publisher: **RNIB E&E**

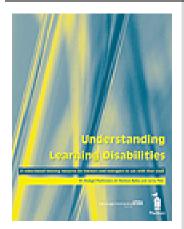
ISBN: N/A

Pub Date: 2001

Price: £1.50

The Asian families project **Sharing learning**

Guidelines for education professionals and RNIB staff dealing with sight problem issues in the Asian community.



Shelagh Author(s):

> MacKinnon, Barbara Bailey

and Lorna Pink RoutledgeFalmer

Publisher:

0415311128

ISBN:

30 OCT 2003

Pub Date:

£22.50

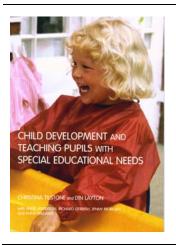
Price:

Understanding Learning Disabilities

A video-based resource for trainers and managers to use with their staff

This new workshop resource is designed for use with direct care staff and others who support or are involved with people with learning disabilities. The workshop was created because of identified training needs that emerged from working with staff and it can either be run in a single day or on a

modular basis.



Author(s): Christina Tilstone

and Lyn Layton

Publisher: RoutledgeFalmer

ISBN: 0415275784

Pub Date: 2004

Price: £16.99

Child Development and Teaching **Pupils with Special Educational** Needs

This book provides a framework for understanding the physical, sensory emotional, social, linguistic and cognitive development of children with special educational needs. It gives practitioners and students a sound grasp of the theoretical ground needed to fully understand cognitive developmental progress in order to optimise learning opportunities.





Assessing functional vision children with complex needs

Catherine Southwell

Royal National Institute of the Hind RN

Author: Catherine Southwell

Publisher: RNIB E&E

ISBN: 1858785987

Pub Date: 2003

Price:

£12.50

Children with complex needs

This booklet explores the different factors that affect what a child sees, such as the size, colour and position of an object, backgrounds, lighting condition and how much time a child is given to make sense of what is presented. The assessment activities have proved useful for assessing children with a wide variety of abilities, needs and interest and are designed to enable you to establish a basline of visual functioning.



Author: RNIB E&E

Publisher: RNIB E&E

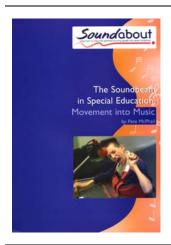
ISBN: N/A - **ED410**

Pub Date: 2003

Price: £2.00

First choice eye contact supplement

This eye contact supplement discusses the importance of choice in the development of communication. It explores the progression of choice making skills for children with visual impairments and multiple disabilities from early observations of preferences through to choosing in more complex situations.



Author: McPhail, P

Publisher: Soundabout

ISBN: N/A

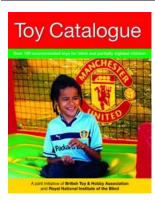
Pub Date: 2003

Price: £12.50

Tel: 01865 744 175

The Soundbeam in special education

Soundbeam technology enables users to create sounds through the smallest movement by interrupting an ultrasonic beam and can open up the potential for creative control to children with the most profound disabilities. This book explains how the technology works and is set up, as well as offering practical examples of techniques and exercises to help you develop the way in which you work with Soundbeam. Consideration is given to particular needs such as cerebral palsy and visual impairment.



Author: RNIB E&E

Publisher: RNIB E&E

ISBN: N/A PR10893

Pub Date: Revised 2003

Price: £0.00

Toy catalogue 2004/05

A brand new edition of this catalogue, which lists more than 100 toys selected for their suitability for blind and partially sighted children.





Author(s): Pauline Heslop &

Carol Robinson

Publisher: York Publishing

Services Ltd

ISBN: 1874291179

Pub Date: 2004

Price: £13.95

Befriending More than just finding friends?

The "Befriending: More than just finding friends" report focuses on the views and experiences of workers at 7 befriending schemes for children and/or adults with learning difficulties in England:, people with learning difficulties using the schemes, their befrienders and parent's of children attached to the schemes.

Quality
Measures for
Befriending
Services



Author: Pauline Heslop

Publisher: York Publishing

Services Ltd

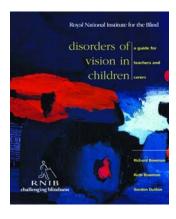
ISBN: 1874291225

Pub Date: 2004

Price: £12.95

Quality Measures for Befriending Services

Quality Measures for Befriending Services is a working tool to help practitioners and managers work towards achieving 'best practice' in key areas of befriending. It was developed from key issues in the report and in conjunction with professionals and practitioners, family carers and people with learning difficulties. At the end of each measure is an action planning grid. Together, the action plans can serve as a record of service improvement and a measure against which to evaluate services.



Author: Richard Bowman.

Ruth Bowman and Gordon Dutton

Publisher: RNIB E&E

ISBN: 1858782139

Pub Date: 2001

Price: £15.00

Disorders of vision in children A guide for teachers and carers

The aim of this valuable book is to explain how disorders of visual function can impair visual performance under different circumstances. Four main chapters cover how eyes and the visual system work, visual function assessment and conditions and diseases of the eye. Educational implications are considered with more detailed and specific educational strategies for visual impairment.

Video

A Billion Seconds. This video shows a 40-minute theatre performance by the Strathcona Theatre Company. It tells the story of Sam, a man with Down syndrome whose father died of cancer, and Sash, a woman with learning disabilities who finds a breast lump. The video is suitable for people with learning disabilities, carers and professionals. Available in 2004.

To order a free copy of the video, please contact BILD, Campion House, Green Street, Kidderminster, Worcestershire DY1O 1JL.





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Short Courses and Conferences

CONTACT DETAILS

BILD

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

2 01562 723025

E-mail: learning@bild.org.uk



Catalyst Education Resources Ltd

1A Potters Cross

Wootton, Bedfordshire MK43 9JG,

U.K.

Further details: **2** 01234 764 108

E-mail: FloCatalyst@aol.com

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Sunfield PDC

Clent Grove, Clent, Nr. Stourbridge, West Midlands DY9 9PB



1 01562 883183

E-mail:

Sunfield@sunfield.worcs.sch.uk

Concept Training

Further details: 15 Beach Street, Morecambe, Lancastshire LA4 6BT



1524 832 828 Fax: 01524 832 852

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

University College Northampton

Further details:

Centre for Professional Development in Education

a 01604 892695 Fax: 01604 714635

E-mail: cpde@northampton.ac.uk Cost: £90 (including Lunch)



14 January 2005

The Sensory brian: The thinking brain

With

Maria Robinson & Flo Longhorn

A look at the earlist levels of intellectual and sensory development

At Birkbeck College, London

Catalyst Education Resources Ltd

Understanding the Multi-Sensory Concept

An inspirational and practical workshop covering all aspects of multi-sensory environments from designing a room and considering health and safety issues through to session planning. The course is clearly delivered, practical and thought provoking.

2005 Programme

East Sussex	The imperial Hotel,Hove	11/01/05
West Midlands	The Portland Hotel, Edgbaston	12/01/05
Nottinghamshire	Westm,inster Hotel, Nottingham	25/01/05
North Yorkshire	Holiday Inn, York	26/01/05
Somerset	Brewhouse Theatre, Taunton	09/02/05
Gloucestershire	The ParkHotel, Falfeild	10/02/05
Strathclyde	Adelphi Cenhtre, Glasgow	22/02/05
Tyne & Wear	Cairn Hotel, Jesmond, Newscatle	23/02/05
Manchester	Haigh Hall, Wigan	08/03/05
South Yorkshire	Carr House Centre, Doncaster	10/03/05

Concept Training







Courses at Tate Britain

Using Handling Resources
For Staff who work with adults
with learning difficulties

Part 1 (support staff only)
Wednesday 16 March 2005
Part 2 (pairs of staff & clients)
Thursday 17 March 2005

This course introduces Tate
Britain's handling boxes. These
provide highly flexible resources
that can be geared to client need.
Handling boxes contain objects
linked to particular works, including
samples of materials, tools and
related images. These help to focus
and prompt discussion and
activities. Boxes can be borrowed
for use at your own pace by staff
and clients. Participants should
have attended an Access 1 course.

Course fee: £30 for parts and 2, including information pack. Clients attend free of charge

To discuss courses & other programmes for community groups in more detail please telephone: Sharon Trotter, Tate Britain on 020 7887 8769 or Alison Cox or Joleen Keizer, Tate Modern on 020 7401 5069/5068



Conferences & Workshops

Oily Cart working with pupils and students with PMLD

2 Day Drama Training Workshop Residential

10th & 11th June 2005 WM Morris School, London 17th & 18th June 2005 Calthorpe School, Birmingham 24th & 25th June 2005 Hadrian School, Newcastle

9.30am - 3.30pm

PE – Success for all 1 Day Training Workshop An inclusive approach to PE and School Sport

> Emmanuel Centre, London 11th February 2005 10.00am – 4.00pm

Inclusion
1Day Training Workshop
Responding to the Inclusive Education

Bonnington in Bloomsbery, Central London 18th March 2005 10.30am – 4.00pm

Autism

1 Day Training Workshop
Responding to the individual Needs of Pupils
with Autistic Spectrum Disorders:
Structured teaching Practice

Bonnington in Bloomsbery, Central London 19th January 2005 10.30am – 4.00pm

SUNFIELD – Professional Development Centre

21st January

Sherbourne Developmental Movement By: George Hill, Sherburne Consultant

27th January

School Based Research in SEN: Finding Evidence - Creating Solutions Conference

By: Dr. Nanette Smith, University College Worcester

Prof. Barry Carpenter, Chief Executive, Sunfield School Prof. Lesley Saunders, Policy Adviser for Research, GTC





SUNFIELD - Professional Development Centre

2nd February

The Keyworking Model

By: Peter Limbrick, Director, Handesel Trust

8th February

Identifying Mental Health Issues in Young People with Intellectual Disabilities

By: Nick Logan, Consultant Psychologist, Sunfield School

9th February

Defining Early Intervention – Interaction Perspectives & Parent Thoughts

By: Barry Carpenter, Chief Executive, Sunfield School







LONGER COURSES (with accreditation)

Master of Arts in Education

Understanding Serve and Profound and Multiple Learning Difficulties (EDUM028)

This module addresses the requirements of the Teacher Training Agency (TTA) National Special Educational Needs Specialist Standards. This accreditation is awarded to students completing the requirements for the three modules EDUM028, EDUM029 and EDUM040. This module is directly related to developing the competencies, knowledge, understanding and critical reflection of students who are, or planning to be Special Education Needs Teachers. The module adheres to the national TTA SEN Specialist Standards (Core and Extension Standards) and students are given opportunities and support to collate evidence to meet the standards. For further Details: University College Northampton. Tel: 01604 892695. E-mail: cpde@northampton.ac.uk

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 a 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: University College Northampton. Tel: 01604 892695. E-mail: cpde@northampton.ac.uk

M.Sc/PG Diploma in Learning Disability Studies 1 year full-time or 2 year part-time course. This course meets the training needs of a variety of professionals involved in delivering services to children or adults with a learning disability, including registered nurses, social workers, doctors, occupational therapists, physiotherapists, speech and language therapists, officers in statutory, voluntary or private establishments, FE tutors, staff of SECs. It provides the opportunity to participate in and contribute to inter-disciplinary learning in a collaborative setting. Further details: Helen Bradley, course director, University of Birmingham, School of Medicine, Tel: 0121 415 8118

Multi-Sensory Impairment

The School of Education offers distance education programmes in multi- sensory impairment leading to an Advanced Certificate (one year), a BPhil (two years), a Postgraduate Certificate



(one year), a Postgraduate Diploma (two years) or a MEd. These courses are designed for those (normally teachers) who work with a learner or learners with multi-sensory impairments. Alongside the BPhil and Postgraduate Diploma programmes qualified teachers may also study for recognition by the DfES as meeting their requirements for mandatory qualification for teachers of deaf-blind children. Further details: University of Birmingham, School of Education Tel: 0121 414 4866

Early years: Sensory and Multiple Needs

This exciting new programme is based in recent developments in early support for children with disabilities. It is designed to enable practitioners working with young children with sensory and multiple needs to work more effectively with this population. Participants from different disciplines will work together to extend co-operative learning and to benefit from others' experiences. Further details: University of Birmingham, School of Education Tel: 0121 414 4866

An Interdisciplinary Approach to Learning Difficulties (severe, Profound & Complex) 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. Further details: University of Birmingham, School of Education Tel: 0121 414 4878

Interdisciplinary work with People with Profound and Multiple Learning Disabilities

A one year distance education course for practitioners and carers of children and adults with profound and multiple learning disabilities. The main focus is upon lifelong learning, communication and effective interdisciplinary collaboration. Offered at three levels: Post experience certificate (level 1), Advanced Certificate (level 3), Postgraduate diploma and Masters (level M) Further details: University of Birmingham, School of Education Tel: 0121 414 4866

MSc in Learning Disabilities

A distance learning course covering all aspects of learning disabilities, however with a strong accent on adults. Consists of nine modules, dissertation and Viva. Each module is assessed by written assignments of varying sizes from 1500 words to 4000 words at level M. Further details: Stuart Cumella/Helen Bradley at the Medical School, Birmingham University.

ACE/Post Grad. Dip/Bphil./MEd.

An Interdisciplinary Approach to Learning Difficulties (Severe, Profound and Complex) A brand new course is planned to commence Sept 2004 in the School of Education at Birmingham University. It will consist of a number of modules and a dissertation depending at which level you are studying. The course is by distance learning methods with tutorial support. Further deatails: Penny Lacey at the Education School, Birmingham University.

Certificate in Working with People who have Learning Disabilities

Distance learning courses from BILD for staff working in the learning disabilities field. Wide range of units available for study. A tutor throughout the course supports each student. Further details: BILD Learning Services Tel: 01562 723010

Profound Learning Disability and Multi Sensory Impairments

A two-year course for parents, carers and professionals which will develop skills and obtain recognition for them. Work is home based, supported by workshops and telephone tutor support. Issues relating to challenging behaviour, communication, education, ordinary life principles, sensory impairment, interdisciplinary working and epilepsy are addressed. The course is offered at three levels: Undergraduate Certificate, Postgraduate Diploma and Masters. Further details: University of Manchester Faculty of Education Tel. 0161 275 3337 E-mail: JTI Office@man.ac.uk www.education.man.ac.uk/pmld/



Report Back

Exploring the benefits of a multi-sensory approach

Delegates from all corners of the UK travelled to Birmingham in October for Concept Training's weekend conference on 'Multi-Sensory Approach to Life and Learning'.

Over the two days of talks, workshop sessions and informal social interaction, the fifty participants were taken through the theory and practice of sensory processing and shown how to develop a multi-sensory approach, while having the chance to meet and share experiences with like-minded people.

Sally Slater set the tone for the weekend with her upbeat and inspirational style. She talked about sensory processing and the difficulties experienced by those with Learning Difficulties and Autism, and helped delegates reflect on the fact that people with severe difficulties are often put into an environment that actually makes sensory processing more difficult. She went on to talk about Sensory Integration and showed a video of a little boy with moderate learning difficulties who was benefiting from Sensory Integration Therapy.

Lunch provided an excellent chance for delegates to network and share experiences and led into a choice of three workshops. 'Inclusive Technology' gave participants an insight into a modern approach that allows people of all abilities to access computer-aided imaging via interactive switches.

'Play and Leisure for Disabled Young People and Adults' was presented by Judy Denziloe from the charity "Action for Leisure". Judy discussed the difference between 'play' and 'leisure' and spoke passionately about the rights of disabled people to enjoy both. Contentious issues such as 'age appropriateness' were discussed and Judy finished the workshop by giving some practical examples of suitable play and leisure activities.

'Mathemagical Resources', facilitated by Les Staves, explained how maths doesn't need to be just calculations, it can also be part of art. Les used music to create moods using clapping and drumming sequences. He then explained, from a very practical point of view, how he tries to get into the mind of a child.

His enthusiastic approach coupled with his great techniques for gaining and holding student's attention made for a fast-moving and entertaining workshop.

Rounding off Saturday afternoon, Judy Denziloe presented 'Sensory on a Shoestring' which introduced a wealth of low cost sensory ideas which left participants buzzing with enthusiasm.

There was the chance to wind down on Saturday night and enjoy some social networking at the conference dinner. The West Bromwich Moat House laid on an excellent meal in pleasant surroundings and diners were treated to balloon modelling and magic from "Silisosage Entertainments" – with everyone going away with a balloon animal.

On Sunday morning the delegates went straight into their choice of workshop sessions. 'Finding the Key to a Multi-Sensory World' gave participants a whistle-stop tour of multi-sensory environments – providing them with practical ideas for the use of sensory equipment, and the confidence to put them into practice with sensitivity, common sense and imagination.

Sally Slater's workshop on 'Creating Life Stories' guided participants through an exploration of the sensory effects of different materials whilst creating a story to suit an individual group, whilst Stephanie Lord in 'Approaches to Relaxation and Managing Anxieties' showed delegates how to monitor their own fears and insecurities. The workshop also allowed participants to create an



action plan they could take back to work that would allow them to create their own calm space to operate in.

Finally, to send the delegates on their way, Stephanie Lord talked about inducing a positive mood, negating the effect of clutter, and creating the optimum environment for learning and living. Stephanie's enthusiastic and inspirational session made sure that the conference finished on a high note.

Janet Price, co-founder of Concept Training, was delighted with the response from participants. "The feedback from delegates was overwhelmingly that the conference had met, and in lots of cases exceeded, their hopes and expectations," said Janet. "They also appreciated the friendly and relaxed atmosphere that allowed them to network with like-minded people. We look forward to organising a follow-on conference next year."

Concept Training's courses and conferences are designed to provide caring professionals with the knowledge, confidence and support to improve the quality of life of service users. From its origins in providing independent training events to help carers make effective use of multi-sensory environments, it has expanded its portfolio to areas that include: inclusive play, reaching out to people with severe learning disabilities, and developing positive approaches to challenging behaviour.

For more information on Concept Training's conferences and courses please visit www.concept-training.co.uk or call 01524 832 828

For press enquiries please contact:

Janet Price or Jack Holliday Concept Training 15 Beach Street Morecambe LA4 6BT 01524 832 828 info@concept-training.co.uk www.concept-training.co.uk Andy Sandford Sticklebacks Communications 13 Dennis Close Redhill RH1 2AX 01737 270 648 andy@sticklebacks.com

The editor of the next PMLD LINK is Beverly Dawkins

'Communication'

The copy date for all articles, information and news for the Spring issue is the 4th February 2005 and the focus is on 'Communication'.

Don't forget to send all contributions to Beverley Dawkins preferably in RTF (Rich Text Format) or 'Microsoft Word' (Beverly contact details are on page 2). If you are also able to supply photographs and/or images to enhance your article please do so, but it is important that the relevant permission to publish is obtained beforehand.