PMLD LINK

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

Winter 2005

Meaningful Engagement

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Meaningful Engagement

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

GUEST EDITORIAL
Summer 2005

Meaningful Engagement

I want to start this editorial by paying tribute to the dedication and enthusiasm of Barry Carpenter who has been a powerful advocate for people with learning difficulties in so many ways in the past thirty years. Readers of the Summer issue will know that Barry has just bowed out as an editor of PMLD Link which he established twenty years ago. I have known Barry for twenty-five years, initially as the Deputy Head in the first special school where I worked, and latterly as the Chief Executive for the remarkable Sunfield School for children with severe and complex learning needs and Director of the Sunfield Research Institute. Barry is a prolific writer of books and articles and regularly contributes to national and international conferences. His constant themes have been the needs of the whole family and developing effective approaches to intervention. Barry's work has been publicly recognised in various ways: for instance, he was recently awarded a personal Chair in Early Childhood Intervention at the University of Worcester, the first such chair in this field in the UK, and, most notably, a well-deserved OBE from the Queen. The editorial team would like to add its own accolade by drawing every reader's attention to Barry's huge contribution to the success of this journal. Our congratulations to Barry for all he has achieved and our best wishes for the excellent work that he continues to do.

This issue has the theme of 'meaningful involvement'. It aims to provide examples of attempts to involve people with profound and multiple learning difficulties in activities that are important emotionally and intellectually to them and that are understandable and make sense. Again, the number and quality of the various contributions was very pleasing and readers will find a range of stimulating examples of the meaningful involvement of children and adults.

The issue begins with articles from members of PAMIS which show how important it is to involve parents and other family members as agents of change and advocates for their relatives who have severe communication difficulties. The issue also includes several articles about approaches to fostering the communication of adults and children, through music therapy, Intensive Interaction and Total Communication and in the context of a specialist feeding programme.

And finally, many thanks to all of the contributors to this issue. Well done!

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Future Focus: Working Together

By Penny Lacey

The next issue of PMLD-Link will have the theme of ‘Working Together’. There are many ways in which this theme can be interpreted. For example, articles could be about:

- professionals/ practitioners working together
- staff working in partnership with people with profound learning difficulties
- services working with families
- families working with schools, colleges and day centres
- residential staff working with day centre or school staff
- people with profound learning difficulties working in partnership with more able peers

There has been enormous interest in multi-agency work recently, especially in children’s services. Not only has ’Every Child Matters’ prompted us all to evaluate how well we work together to protect the most vulnerable in our society but the Early Support Programme has actually provided the impetus for trialling ways of working together more effectively. Hopefully Children’s Trusts (or something similar) will take joint working even further.

For some time now, in adult services, health and social care have been struggling to work in a more integrated way. In some areas there are now multidisciplinary teams with responsibility for learning disability but in other areas there are still single services whose structures makes it difficult to share with each other.

We would love to hear examples of practice from children’s and adult services where people are working together across boundaries to meet the needs of people with PMLD. How does it work in your service? What are the difficulties you face in trying to work together? What sorts of things seem to make the task easier?

Although multi-agency work is a hot topic, there are many other aspects to working together. How about any good stories about people with PMLD in partnership with more able people with learning disabilities? Does that happen where you work? How about intensive interaction between two people with learning disabilities: does that happen and could you write about it?

And what about families? Can anyone provide a story about family life when attempting to work together with other people? Is there a family who has a keyworker who would be prepared to tell us of their experience? The Government is now convinced that keyworking is important but, of course, there is no extra money to support it in practice, so does it work?

Please send us your contributions on anything related to ‘working together’.

Penny Lacey (Guest Editor: Spring Edition on ‘Working Together’)
Senior Lecturer in Education, The University of Birmingham, School of Education

Understanding the emotional and mental well-being of people with profound and multiple learning disabilities

by Loretto Lambe and Maureen Phillip
University of Dundee

'I know it's difficult to describe the changes in her facial expressions, because you know the changes are so subtle, but very noticeable. When she's happy you certainly know she's happy and she lets everybody know she's happy, because she sings at the top of her voice. The tone changes with changes in her emotional and mental well-being, just a slight difference; it's like the difference between somebody singing a lament and singing

This quote is from a parent who participated in the Well-Being Project. Family carers were central to this project as they have a pivotal role in identifying and supporting a family member who experiences changes in emotional and mental well-being.

There is a growing awareness that young people with profound and multiple learning disabilities suffer from depression, anxiety and stress, as do many other individuals. Because they cannot talk about their difficulties these may be overlooked by those who care for them.

The two-year project was funded by *The Foundation for People with Learning Disabilities* (FPLD) and carried out by The White Top Research Unit, University of Dundee, to investigate how family carers and care staff identify and respond to changes in the mental and emotional well-being of these young people. The project also explored what service support was sought by and available to family carers and care staff.

Professor James Hogg and Jill Davies talked about the project in a previous article for PMLD Link in 2004 and this article provides an update of the progress of the project.

The research findings highlighted key areas in which information and training for family carers and care staff are required. These provided the basis of a training workshop which was designed and run for family carers and care staff by parents in partnership with the White Top Research Unit and *PAMIS (Promoting a More Inclusive Society)* the voluntary agency in Scotland representing individuals and parents and families of people with profound and multiple learning disabilities. The workshop is interactive and uses case studies from the research to explore sensitive and emotional areas of well-being, as well as possible pathways of support.

Identification and interviewing of family carers and care staff

The first phase of the work was to identify people with profound and multiple learning disabilities living in the Tayside region of Scotland, who were experiencing, or who had previously experienced, emotional or mental well-being problems. This was achieved through approaching family carers who had indicated the presence of such problems in their sons or daughters as part of the Tayside Profound Disability Survey, a 10 year follow-up survey of 150 children and adults with profound and multiple learning disabilities who were identified in 1993.

Because of the small number of individuals identified by this survey who met the necessary criteria regarding age range (13-29 years), who had experience of changes in emotional and mental well-being and were willing to participate in the research, the study had to be extended to the Fife region of Scotland. This proved successful, resulting in a total of 13 young people participating in the study. Eight parental interviews and eight care staff interviews were completed (for 3 young people, both their parent and member of the care staff from a residential home or day service were interviewed).

Visits to family homes and day services were arranged and carers who agreed to participate in the study were asked to complete the Mini PAS-ADD which is an assessment schedule for the detection of mental health problems in adults with developmental disabilities. Completing this assessment schedule gave the carers an opportunity to think about and discuss the concepts of emotional and mental well-being before being interviewed. Once the assessment schedule had been completed, the carers were interviewed using a semi-structured interview schedule. The interviews were recorded on tape.

The semi-structured interview schedule was designed to ask questions about possible causes and effects of changes in emotional and mental well-being, as well as what help was available to the carers if a change was identified. It was felt that questions relating to the availability of help would be beneficial to identifying clear pathways of help for the carers. Interview responses, together with data from the PAS-ADD assessments and workshop sessions, were analysed and four categories emerged: cause, how the symptoms of affective disorders are demonstrated, available help and future help.

During the information-gathering process consideration had to be given to the sensitivity of the topic and the high healthcare needs of the young people. Often the interviews were interrupted because of these needs, which meant that in most cases several visits were required to complete the interview process. Family carers are often very stressed and find that few people have time to listen to their problems, so for them this project offered the opportunity to talk about their concerns.

The workshop development

Although a wide range of causes were responsible for changes in emotional and mental well-being, four topics were chosen from the research to be developed into a workshop programe

Change and transition
Health and mental well-being
Loss and bereavement
Supportive therapies

Family carers were then given the opportunity to be involved in the design and development of the workshop. A strategy and planning meeting was held and a training group was formed. An external trainer, Ellenor Curry, was employed to train the group. The training group had three days intensive training during which they had to learn how to facilitate a training session, plan their four sessions, agree on the methods to be used and consider their resources. It was decided that the workshop would be based on the *PAMIS* model, which is held one day a week over three weeks at parent friendly times and help with transport costs is provided. There is always a participants' pack and the workshops are evaluated. The group decided to combine guided tasks with case studies from the research to present the workshop.

Change and Transition.

This session began by asking participants to think about how events and experiences in their own lives had influenced or changed their own emotional and mental well-being. They were then asked to think about how they would convey these emotions if they could not speak.

Two case studies from the research were presented by parents of two young men who had experienced dramatic changes in their emotional and mental well-being during periods of change and transition. The participants then had to complete two exercises taken from other case studies from the research. Feedback was given and the session finished with a group discussion about how family carers and support staff can helpfully respond to identified changes in emotional and mental well-being of people with profound and multiple learning disabilities.

Learning outcomes from this session:

- Participants would be able to identify some causes and effects of changes in the emotional and mental well-being
- Describe a range of responses
- Determine ways in which services can help minimize disruption and distress caused by periods of change and transition.

Health issues impacting on emotional and mental well-being

This session was presented by two parents who talked about how physical and mental health interlink. The trainers began by introducing themselves and their sons, they talked about the impact of physical health on emotional and mental well-being and how poor mental health can lead to physical health care problems. Group exercises were then completed after hearing the two case studies and participants were asked to identify the triggers for the change in the emotional and mental well-being of the two young men. Participants were also asked to identify some symptoms and responses the young men experienced and also what symptoms and responses might the family carers suffer during this time. After considering all the information the group were asked to design personal action plan of support. In the action plan for professionals the following considerations were asked :

- that professionals continued to build on current good practice of improving the physical health of people with profound and multiple learning disabilities.
- that professionals continued to improve their recognition and responses to mental health issues that may affect people with profound and multiple learning disabilities with whom they work
- that these principles be included in service's mission statements.

Learning outcomes from this session:

- Identification of the impact of changes in physical, emotional and mental well-being
- An awareness of how physical and emotional well-being impact on each other
- Describe some key triggers to changes in the health of people with profound and multiple learning disabilities
- Identify a person's symptoms and responses to changes in health and describe the likely impact on family carers
- Devise a personal action plan for improving the health of people with profound and multiple learning disabilities and their family carers.

Loss and Bereavement

This session was presented by a parent and the *PAMIS* co-ordinator for Fife with support from a *PAMIS* volunteer. Because of the sensitive nature of this topic it was carefully placed third out of four sessions in the overall workshop.

Grief for someone much loved is a very powerful emotional event and poses a fundamental challenge to our emotional and mental well-being. However we may not fully realise that people with profound and multiple learning disabilities will also feel grief and it is easy to miss the ways in which they express their feelings. Their needs at this stressful time can pose a very difficult challenge to others in the family who are also trying to come to terms with their own feelings of loss. This session explored a number of different themes and devised a blueprint of support for people with profound and multiple learning disabilities and their families.

Themes explored

- Recognising the discomfort participants might feel in approaching the subject. Exercises were designed to help participants to feel comfortable enough to begin discussions.
- A brief presentation looking at recent changes in thinking about the process of grief
- Participants were then asked to try and imagine what it might be like to be a person with profound and multiple learning disabilities, losing someone they loved but being unable to express their feelings without the using language.
- A case study was then presented by the parent trainer. The case study described the effect the death of a grandparent had on this young man, who has profound and multiple learning disabilities, and the ways in which the family supported him.
- A blueprint of support was devised from this session.

Learning outcomes from this session

- Participants will be able to describe their own feelings when talking about loss and bereavement
- Identify feelings associated with loss
- Describe some ways in which a person with profound and multiple learning disabilities might react to the loss of someone important to them and how they may express this without words
- Identify support which an individual and their family might need to cope with loss

and bereavement and how this support might be provided.

Supportive therapies

This session again used two case studies from the research and two parents presented the session. They discussed the positive and negative effect that music had on their daughters and the use of music as a mood indicator. The use of complimentary and supportive therapies as an aid to improving the overall well-being of people with profound and multiple learning disabilities was also included in this session.

Participants had to identify a range of complimentary and supportive therapies and think about the positive and negative effects of using them. The parents then presented their case studies, highlighting the therapies that they had used with their daughters. The process of choosing a therapist was discussed and an individual action plan for finding out or accessing complimentary therapists was developed.

This session includes a video clip of the effect music has on one young woman with profound and multiple learning disabilities.

Learning outcomes from this session

- Identification of complimentary and supportive therapies
- Identification of benefits and drawbacks of using complimentary and supportive therapies
- Identification of possible benefit and drawbacks of using music to aid the well-being of people with profound and multiple learning disabilities
- Participants will be able to describe ways of accessing complimentary and supportive therapies and choosing a therapist

People with profound and multiple learning disabilities experience changes in emotional and mental well-being just like everyone else but their symptoms and responses can vary, therefore those that care for them need to be aware of this and to also think about what factors might contribute to changes in emotional and mental well-being. The well-being training workshops have proven to be very effective in dealing with this.

To date the training workshops have been delivered to family carers in Fife and to a mixed group of family carers, frontline workers and teachers in Tayside. Later in the year the workshop will be delivered to service providers in Fife. The findings of the research have been published in the *Making Us Count* report (FPLD, 2005) and the training workshop will be available (FPLD, in press) as a multi-media CD ROM later this year. The parents that delivered this training workshop have also spoken at several FPLD seminars.

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FPLD (2005) *Making Us Count* London: Foundation for People with Learning Disabilities

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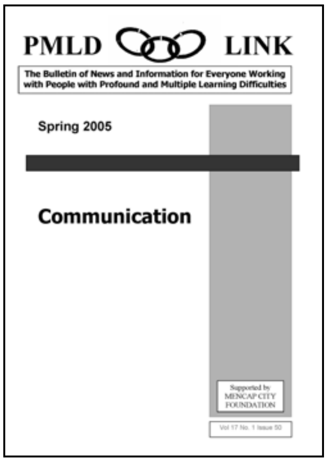

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Spring 2005

Communication

Good Practice in Consulting Family Carers

by Jessie Roberts, PAMIS Co-ordinator, Fife

For the last few years, four young people with profound and multiple learning disabilities and complex health needs have been attending a small specialist day service near Dunfermline in Fife. Their families feel that it offers a high quality, person-centred approach, with excellent links between themselves and staff. The service operates from a bungalow in a residential area, and supports the young people to join in a wide range of community activities, and the bungalow is also used for an indoor programme, as well as a safe place to meet health and personal care needs. Aberlour Childcare Trust runs the service, but cannot continue to do so after the adults reach 25 years.

The young adults have no speech and profound learning disabilities. They do have many individual ways of making their views known, especially through facial expressions, gestures and behaviour. But they are heavily dependent on the people who know them best to interpret the way in which they express themselves and to make sense of the world. Their families are therefore key advocates on their behalf.

All of the families whose daughter or son will be moving on are represented on the Reprovisioning Group set up to establish a replacement service. They are key partners in a multi-disciplinary team, with staff from Fife Council, NHS Fife and the voluntary sector. I have been a member of the Group as Fife Co-ordinator for *PAMIS,* the Scottish-based registered charity which supports families caring for a child or adult with profound and multiple learning disabilities.

One parent said that the prospect of change was very stressful, especially after “we had battled long and hard for the provision to be set up.” However:

> *“I feel that they have encouraged us to participate in the decision-making process - we have been consulted and involved at every stage, our views and opinions have been listened to. We have really worked in partnership and I hope that the outcome will be a service which meets all of my daughter’s needs, enables her to reach her full potential and have a good quality of life.”*

Families attended all meetings, wrote the service specification, and visited potential providers. They helped select providers for interview and were on the interview panel. Another parent said:

> *“We were consulted at every stage of the reprovision process including being invited to the presentations given by each of 3 service providers asked to submit tenders. We had a discussion after each presentation and individually scored each provider.”*

The Group required the successful provider to continue to work in close partnership with families. Capability Scotland has now been chosen, and will for example involve families in staff selection and the choice of a building base. Ultimately families’ views determined the selection of the provider, backed by Fife Council when it would have been easier for management to make a different choice.

The families wrote to Fife’s Head of Social Work Service to praise this work as an example of good practice in consultation. The work of the Group has been formally recognised recently by an award by the Scottish Social Services Council Care Accolades in the category of ‘*Best Involvement of People who UseServices’*.

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A shorter version of this article appeared as a case study of good practice in the Scottish Executive’s Report on Day Services (2005).

The Evolution of a Music Therapy Group

By Catrin Piears, Music Therapist

This article gives a narrative account of two and half years of a music therapy group consisting of people with multiple disabilities attending a 'Parity for Disability' day centre. The group's journey through engaging with others, adjusting to, experiencing and surviving change enabled individuals' confidence and awareness of their impact on others, to emerge from the exploration of meaningful and musical involvement.

The ability to respond to music is inborn and usually unaffected by disability, injury or illness: music therapists acknowledge and use the unique qualities of music to reflect and connect with their clients. This music therapy group was set up to complement the individual work offered by the day centre. Through explorative and structured music making the music therapy group could concentrate on developing meaningful peer interaction and relationship skills in a social environment. The members in this music therapy group were given the opportunity to develop awareness and toleration of others, to explore aspects of non-verbal communication, and to influence those around them through music making.

Starting out

The group consisted of Rebecca, a wheelchair user who used facial expression and gesture to communicate, needed some assistance in accessing the instruments and had experienced a music therapy group previously; Alison, also a wheelchair user, who experienced some difficulty in using her hands, chatty and new to the group: Stuart – a wheelchair user needing some assistance in the positioning of instruments, a man of few words but laughter for all and previous experience of music therapy: Caroline, a keyworker in the day centre who assisted in the group every week, and myself, the facilitator and music therapist.

Starting out, the group relied on a solid structure of activities to encourage group members' listening skills and provide a predictable environment in which group members could relax and explore their musical skills. These activities included choosing instruments, passing sounds by taking turns on instruments, 'follow the leader' type musical games and themed musical improvisations based on events, weather and scenarios. The sessions were paced around the group members' involvement and soon Rebecca, Alison and Stuart became familiar with our Monday meetings. After a few months it began to feel that our usual half hour session was just not long enough for everyone to have time to play. I suggested that the group could decide whether they wanted the session time to extend to forty-five minutes. Alison and Stuart were keen to have a longer session and were able to tell the group, and Rebecca communicated her thoughts by gesturing her agreement with Alison and Stuart. Success -our first group decision made!

Around this time Caroline passed her assistant duties on to Mel so our group meetings involved adjustment for everyone: Rebecca and Stuart were confident in their involvement in the activities, having been in a music therapy group before, yet were still getting to know me and Alison. Alison was adjusting to her new experience of the group, and we were all getting to know Mel in her new role as the assistant. Having these changes in our first few months together as a group meant that the increased time was needed to offer the group more stability and scope to relax and reflect together on these recent events. The group grew in confidence and developed patience in waiting and listening to each other choose and play instruments. They also began to develop the capacity to choose instruments for each other as well as to think of themes to play music about. Rebecca, Alison and Stuart participated in the group as they felt comfortable and Mel physically supported instruments for them if needed. Group members were free to play as little or as much as they felt able within the context of the activities.

The group developed a greater sense of solidarity over the next few months; Alison relaxed more and a sense of kinship evolved in the group relations. The two ‘veterans’ Rebecca and Stuart, were responding musically to Alison and she herself was beginning to relate to them verbally when at first she only felt able to comment to Mel and myself. Over this first year the group developed their listening skills; managing to wait for each other taking turns and learning to allow Rebecca, with more physical needs than the others, plenty of time to respond. In turn, Rebecca’s anxiety in relation to her frustration at sounding instruments reduced as she came to trust that we would wait for her.

A period of change

The music therapy group was running smoothly and confidently a year on from the start. Around this time, possibilities to link Parity’s two day centres were suggested, and it seemed the right time to see whether the group could consider welcoming a new member. At first Rebecca, Alison and Stuart seemed apprehensive and were reluctant to make their thoughts known as though they thought that the decision had already been made for them. I was careful to stress that their opinions were important and reminded them of the previous changes we had worked through. The group were comfortable working together and perhaps there was fear that any change would alter this security. However, there was also a sense of excited anticipation in the group; their playing was strong and their communication clear. In one session around this time Mel was absent, so Caroline, our previous assistant joined us instead. All group members were playing their instruments to their best ability and demonstrating their skills with a renewed pride that I had not witnessed before; it was as if they were showing Caroline how much they had developed as a group since she had last seen them together. It was this confidence displayed in the group that made me realise perhaps a new group member could harness this enthusiasm further and exercise their self-assurance.

Unfortunately, due to building works, our venue for the group was compromised and for a few weeks we met in a room across the road from the day centre. Adapting to a new venue, the possibility of a new group member and several bank holidays disrupting the consistency of our meetings, shook the foundations of the group a little, but it felt all the more important to acknowledge the changes, and state that the group was still continuing to meet and play music together despite these difficulties. In between our musical activities I would acknowledge these changes verbally, and Alison in particular would verbally express her feelings concerning the changes in response. Stuart began to confidently vocalise when he agreed with what was being said, which would then prompt me to ask whether Rebecca agreed or disagreed: she would usually gesture a clear positive or negative or respond with a suggestion of uncertainty or indifference. There were mixed feelings around the integration of a new member, but it really felt like the group were finding ways to adapt to, rather than reject, change.

Over a few weeks of introducing the idea of a new group member, and acknowledging how this may impact the group, Rebecca, Alison and Stuart welcomed new group member Natasha into the music therapy group. Natasha was physically very able though a little shy, and responded well to Mel and myself, bringing some energy to the group in her playing and humour with her witty remarks. Alison was able to share her previous experience of being the newest member of the group, and Rebecca and Stuart used their newfound confidence to demonstrate the activities and support Natasha. The experienced group members looked towards Natasha in activities, chose her to lead the music, demonstrated their own skills better than I had witnessed before and were concerned if she was absent for any reason. It was certainly a time of change, and again the group demonstrated any difficulties they were experiencing by verbalising their concerns, withdrawing from the music or looking towards each other, Mel and myself for responses and support.

The group seemed to be using these new changes to reinforce their own confidence and ability to adapt. The musical activities maintained the familiar structure yet within the music itself students were encouraged to play as they liked, exploring their individual sounds at their own pace. All four group members were more inclined to choose new and different instruments and play longer pieces together. The potential of the group was shining! It felt possible to focus on the positive atmosphere within the group as well as acknowledging people's concerns if they arose. Self-expression in our joint music-making was becoming more possible and, therefore, each week it was now suggested that a different group member would choose whether they wanted to play a relaxing or lively piece, reflecting how they might be feeling. The other group members would then play the music in the manner that had been chosen, consequently beginning to support each other in their music even when they may be feeling different themselves. We thought how we might like relaxing music when feeling tired or sad, and how lively music might wake us up or feel good when we are happy.

Intensity and depth

Then some good news came in that the day centre would be permanently moving to the building in which we were holding the music therapy group. As we met after the move was complete, there was at once a more settled feel to the group and it seemed we had survived much change by continuing to meet, acknowledging the changes and how those changes made us feel. It was also important to acknowledge group members when absent from the group on holidays, or when sick, as it became clearly apparent that the present group members missed, or worried about absentees, which in turn raised issues regarding group members' experiences of loss. The expression of concern for others demonstrated how close the group had become, and how tolerant of each other they could be. As we continued to think about playing music concerning group members' feelings alongside our usual activities, Rebecca, Alison, Stuart and Natasha began to be more open about events for them that were difficult. Openly acknowledging Rebecca's changes in facial expression, and gesture, in response to any chat that occurred was an important part of drawing her into discussions between our music, and also assisting all the group members to relate to each other.

Rebecca, Alison, Stuart and Natasha were starting to share their concerns during our time together, perhaps safe in the knowledge that they would be supported and that music could offer one way of expressing feelings. Issues such as loved ones going on holiday, loved ones being ill, possessions being mislaid, new carers arriving, as well as upcoming holidays and parties were brought by group members, and we made up music together taking into account how these events made us feel. The music about feelings was played in the middle of the session, framed by well-known activities so that group members could securely explore this fairly new way of working.

Again the group embraced a new way of making music and also displayed increased concern for others in the group. They would physically reach out to each other in support and also vocalise or respond verbally to group members who had brought issues to think about. Activity based music making reduced and spontaneous musical improvisations, based on how the group were feeling, increased. Rebecca, Alison, Stuart and Natasha continued to explore their musical input and demonstrate their individuality in their playing: they also proved their confidence to improvise without necessarily determining a theme but instead relying on their own feelings and musicality. Sometimes group members commented on the music. However, the strength of the group and sense of achievement in their growth seemed to uphold the groups' confidence in their music making alone. The music said it all.

Final phase

The final chapter of the group was brought about my move to different employment. Preparation for the end of the group as we knew it was considered over several weeks and feelings such as anger and sadness in my leaving were considered and expressed in the music and acknowledged with support. Ultimately the group were confident in managing the ending together and considering what this meant for them. Seemingly, the strength gained by the group members over the period we had worked together had given Rebecca, Alison, Stuart and Natasha the capacity to explore how they felt about this major change, with one another and with me. Looking back on the life and development of the group has been important, and reflecting on how relationships and especially the music in the group have evolved, has been a positive way of adjusting to the unexpected conclusion of the group.

My experience of the music therapy group over its two and half year life was of seized opportunities and self-belief. It seemed that when changes occurred the group members used each other to grow in managing these changes, enabling themselves to explore emotional expression in their music brought about by actual events. Individuals furthered their awareness and tolerance of each other through predominantly non-verbal means of communication and expression. Coping with, and managing, change has been an important outcome for the group and their developing strength has enabled them to use each other for personal support. The group experience has provided much food for thought for theoretical analysis and professional development. However I have found that collecting together a narrative of the group over this time has been an enriching process of personal reflection that has acknowledged the group members' struggles and strengths involved in being part of a group. Fortunately there will be the continued opportunity for a music therapy group at Parity led by my successor; enabling more service users to embrace the opportunity to engage in meaningful involvement, communication, social interaction, support and emotional expression through joint music-making.

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Parity for Disability is an independent organisation providing services and information for over 100 children and young adults with multiple disabilities in Hampshire, Surrey and Berkshire. Parity is dedicated to making the image of disability a more positive one, and to enabling people with multiple disabilities to become integrated into the community and access mainstream services. Contact Parity for Disability at 94 Whetstone Road, Cove, Farnborough, Hampshire GU14 9SX. Tel: 01252 375581.

Email info@parityfordisability.org.uk or visit www.parityfordisability.org.uk

Useful Books:

Bunt, L. and Hoskyns, S. (2002) (eds) *The Handbook of Music Therapy* London: Taylor and Francis.

Davies, A and Richards, E. (2002) (eds) *Music Therapy and Group Work – Sound Company* London: Jessica Kingsley Publishers.

The editor of the **Summer edition** of PMLD LINK is

Julia Dixon
'Early Years'

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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).

Meeting the developmental needs of a group of children while they receive their enteral feeds at school

by Wendy Mogridge, Special School Nurse

I work within a team of nurses at a special school which caters for children from 2 ½ to 19 years. The children have a range of learning difficulties, from severe to profound and multiple (PMLD). Many of the children also have complex medical needs. As part of my role I regularly administer enteral feeds to a group of children with PMLD and complex medical needs. Enteral feeds are specially formulated liquid feeds which are administered directly into the stomach either through a naso-gastric tube or a gastrostomy tube.

I identified that during enteral feeds, my colleagues and I were administering the feeds in a safe manner, but the environment that we were providing did not meet the individual needs of the children. I was keen to create an environment which facilitates communication and social interaction, values the children's contributions and shows them dignity and respect (a fundamental right as identified by Ware, 2003). This is the process I went through.

Identifying the need for change.

The environment in which the children are fed was noisy, the nurses would often talk amongst themselves and the radio was always playing lively 'pop' music in the background. There were frequent interruptions from staff and children requiring non-urgent attention. The feeds were often rushed because of the number of children requiring feeds, and the environment was cramped and cluttered.

It is important that children do not miss out on the social aspect of mealtimes, but for this group of children, the regime provided little opportunity for social interaction and they received insufficient attention and no opportunity for learning and progression whilst receiving feeds. I was aware that communication was not a priority, and felt that if the nursing team continued to fail to recognise the children's efforts to communicate, the children may then stop attempting to communicate. I noted that the nursing team were feeding the children using a medical model of care with little consideration for their educational needs.

The Aims

The need for change was evident. Children are entitled to an environment which values and respects them, recognises their individual strengths and 'listens' to them (Ware, 2003). I therefore set about creating a calm environment which allows the children to develop in all areas.

The children had little opportunity to demonstrate the communication skills that they possess, mainly because the nursing staff lacked the ability to understand their attempts at communication, and children only have the potential to develop communication if they are given every opportunity to interact with people who 'listen'. It was my aim to identify how each child communicates.

Homan (1997) states that the 1994 SEN Code of Practice (DfEE, 1994) clarifies that children should be given the opportunity to make the maximum progress possible with no exclusion from any activity or the curriculum because of 'treatment'. It was not viable to feed the children in the classrooms with their peers, but we could ensure that the children were given the opportunities to make progress by altering the environment to meet their needs.

My aim was to create an environment where knowledge is shared between the different agencies so that we can maximise learning opportunities for every child in our care. I hoped to create an environment which is responsive, supportive, and educational and focuses on abilities and strengths of each child.

Identifying potential barriers to change

I discussed my concerns about the situation with my colleagues, and although they agreed that we may not be meeting the children's needs, they were also concerned about the implications that introducing new ideas and responsibilities may have on their time. I was keen to avoid criticising past practice and focus on improvements for the future, and therefore I arranged a team meeting to identify what the concerns were and how we might overcome them. If I was to make a difference to the input that the children were receiving, I would need full support from my colleagues. I just hoped that I could maintain motivation by providing the evidence that my suggestions were effective.

Assessing the needs of the children

Assessment was needed to provide a baseline of information about each child's current skills, and their ability to communicate. This enabled the team to set realistic future targets. Initially, I was aware that although this was the children's mealtime, they were not receiving oral stimulation, contrary to the evidence of Evans-Morris and Dunn-Klein (2000) who highlight the importance of sensory development through oral experiences. My first contact for advice was the speech and language therapist (SLT). We discussed each child individually and she agreed to help me to undertake an assessment of the appropriateness of the nursing team carrying out an oral stimulation programme during enteral feeding. As a result of this initial assessment, both the SLT and I concluded that all of the children had negative feelings associated with their mouths and faces as a result of years of invasive procedures, including the use of naso-gastric tubes and oral suction. The SLT recommended that we carry out a programme of desensitisation in the future, but not until a calmer environment had been achieved, and not during mealtimes.

I briefly discussed the needs, abilities and levels of communication of the children with their teachers. Finally, the nursing team carried out observations of the children while being fed; this was carried out over one week. Unfortunately, this assessment process was short, unstructured and frequently interrupted. However, it was a necessary process in order for me to establish an understanding of what the children's behaviours meant, whether they were communicating and which behaviours were voluntary. I was surprised that our observations identified a consistent pattern of responses from some of the children; responses that had not previously been considered as communication.

Having established that the children were capable of communicating, the next challenge was to create an environment to facilitate this. It was evident that the nurses were missing the cues for communication that the children were giving us.

Corke's (2002) work on interactive music with children with PMLD prompted me to investigate the use of music to create a calm environment that facilitates learning and development. Armed with the evidence, my colleagues agreed that this would provide the basis for our initial attempt to create a calm environment that was conducive to learning.

Implementing the programme.

Having identified that the room was cluttered and untidy, my first priority was to tidy it. The team organised the room so that the emergency equipment was easily accessible, and each child had their own space, but was also part of the group.

We observed the children in an attempt to elicit each child's response to their environment, and each child's method of communication. We agreed that we needed further training on how to interact with the children; I agreed to read up about this and report back to the team. In order to communicate at an appropriate level for the children I recommended that we used exaggerated speech, exaggerated facial expressions (for the children who could see), and touch (for those who were comfortable with it) taking the lead from the child where possible as recommended by Ware (2003). We increased the pause between speech and actions, to encourage a response, and we commented on actions the child made.

Through my reading I became aware of the profound effect that music can have on a child's social, emotional and educational development, and suggested to the nursing team that we could try to create a calm and relaxed environment using classical music. In spite of my apprehensions, my colleagues agreed. My choice of classical music was influenced by Buckwalter, Hartsock and Gaffney (1985) who suggested that stimulative music is likely to produce higher levels of anxiety, physiological arousal and aggression than classical music. According to the literature, music can be introduced cheaply, and without the need for extensive training, this suited an already busy and under funded medical department.

The nurses talked to the children demonstrating that they valued them and expected a response, they also informed the children of what they were doing, thus attempting to prepare the children for physical contact during feeding. Once the feeds were set up, I introduced the music. Conversation was kept to a minimum, but when a child moved or vocalised we responded and then waited to allow them time to respond back. A notice was put up outside the medical department during 'mealtimes' to request that we were not disturbed unless it was an emergency.

Evaluation

The nursing team have gone a long way in improving the conditions for the children by providing an environment that is calmer and more responsive to needs of the individuals. However, because of the time limitations, I am aware that there are areas of weakness and areas requiring further development.

My study would have benefited from more structured observation and assessment, with a greater request for support from the education staff and parents. I am also aware that we need further training in communicating with children with PMLD.

However, I have been grateful for the positive involvement and support of my colleagues. We are enthusiastic about making a difference to the quality of life of the children in our care, and intend to continue to monitor and improve the conditions within the medical department.

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Creative Communication

by Kate Duncalfe, Learning Disability Consultation Worker

When I was younger I wanted to be Kylie…no a vet... no a teacher…a nurse …a journalist, writer, actor, the list goes on! My dreams were big for a 9 year old but, like all of us, I dreamed of what I knew. I'm sure if I had known that I could be a "Learning Disability Consultation Worker" I would have said that from the start! Ok maybe not, but there is someone whose presence in my life has made me a "Learning Disability Consultation Worker" and like me, he didn't even know what one was! That's because titles and labels are not important. I am a LDCW, I work with people with PMLD and I go to the LDPB (Learning Disability Partnership Board). The greatest influence on my life wouldn't understand and care about those acronyms or what they stand for. My job is about individuals and their unique communication, that is what is important.

The man who has shaped me so much is my uncle. He is a man of few words and they are of his own design. But he can communicate everything that is important, feelings, needs and what he wants at the pub! Knowing him inspired me to work with people with learning disabilities and it was during this work that I realised that not everyone with PMLD is seen as being able to communicate. Something my uncle would do to show excitement or anger, could be seen as "bad behaviour". Why? We all have these emotions, and as adults we are not told we are "naughty" for expressing them. Just because we have a nice tidy way of expressing how we feel that doesn't make our way of communicating any better or make people who can verbalise any "better behaved". We know when my uncle is angry and he can show what is upsetting him, he wants to explain. Far less "badly behaved" and easier to understand than me as teenager!

Communication strategies often miss out people with PMLD. Bigger text means nothing if you cannot read; pictures and cards only work if you can see and understand what that picture represents; and Makaton only works if you can control your fine hand movement. There are more fantastic and effective communication tools for people with leaning disabilities. But where does that leave the people with PMLD, people who have just as much to say?

The problem is that often, as people who provide a service to people with PMLD, we are trying to impose communication methods we have designed on people to find out what we want to know and what we consider important. I went into this job with the intention of helping people with PMLD to communicate. I was meant to involve people in the big issues; housing, day centre modernisation, transport. I soon realised that people with PMLD already communicate. Really my job was to work with them to enable them to share their communication, and teach the people around them to listen to what really affected their lives.

Sensory stimulation is very important. Someone may not be able to tell you who they want to live with, but they may show you through their behaviour that they do not like loud noises and they may therefore prefer living with quiet people. Someone may not be able to point to the tea or coffee, or tell you how many sugars they want; make them all and see which doesn't get spat out! Someone may love to watch the lights in the sensory room; could they have lights above their bed at home? For some people it is just nice to have someone communicate with them in their way, just for communication's sake; if someone taps on the side of their chair, do the same and see how they react! This may not be communicating anything in particular, but how many of you chat about the weather for no reason?

These are very simplistic examples and communication is often much more subtle and complex. It can take months even years of work. The idea is that this work is controlled by the individual, so therefore it is impossible to write an example for the person you have in your mind at this moment. This is the ethos behind Doncaster's "Total Communication Strategy" and the training I offer based on it called "Creative Communication". The communication strategy was written by a group of people including a person centred planning co-ordinator, a speech and language therapist, an advocacy worker and myself. The group relied heavily on consultation about communication with people with a range of learning disabilities. My role on this group was to add in the creative, less traditional methods for use with people with PMLD. Through their involvement we discovered a communication strategy should not be a prescriptive set of symbols; it should be a guide and encouragement for the people who know the person with PMLD to think creatively and outside the box about communication.

If you are interested in the training (which includes a copy of Doncaster's copyrighted "Total Communication Strategy" for each attendee) then please do not hesitate to contact me.

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Kingsley Communication – Enabling all pupils to communicate

by Kevin Latham, Assistant Head and Communication Coordinator Kingsley Community Primary Special School

Introduction

During the autumn term 2003 Kingsley school re-structured its classes to integrate pupils with profound and multiple learning difficulties (PMLD) who had up until then been taught in a specialist class. The school undertook a series of training sessions devoted to optimal teaching and learning styles which facilitated fully differentiated lessons (giving pupils the opportunity to access lessons and learn through their favoured style; visual, auditory, kinaesthetic), which the Department for Education and Skills (DfES) has now termed individual learning programmes (DfES 2004) and is introducing to mainstream schools. Throughout the following months analysis of pupil involvement, using Primary Effective Early Learning (PEEL) Programme (Centre for Research in Early Childhood, University College of Worcester 1995), was undertaken to look at the levels of involvement and types of interactions of pupils with PMLD within the mixed ability groups. Levels of involvement were noticeably lower within the PMLD population and interactions were predominantly adult initiated. There were also very few interactions with other pupils.

The staff at Kingsley were acutely aware of this issue and after discussions it was highlighted that a major factor was the quality of communication. A voluntary group of staff from across the school decided to meet to discuss the provision for objects of reference. The remit of the group changed before the first meeting to look at the provision for communication for all pupils across the school, whatever their formal mode of communication (speech, sign, symbol, photographs) including objects of reference. The issue of informal modes of communication (vocalisations, gestures etc) was to be picked up through the use of communication passports being introduced by the speech and language therapists.

The communication group, including teachers, class staff and a speech and language therapy assistant, set a clear aim for their work: to put in place systems enabling all pupils to communicate in their preferred mode with all people in the school (pupils and staff) and wherever they are in the school. Initially this seemed a simple prospect, but after only a few minutes of discussion the enormity of the task revealed itself. The group would have to take into account pupils who use speech, signing, symbols, photographs and objects of reference; and how to put in place a system to enable pupils with complex communication difficulties to talk to each other – in the class room, on the playground or in the dining hall.

Before the communication group could start to discuss any systems the highly contentious issue of standardising communication had to be resolved – if communication is not standardised then it cannot be a formal mode of communication and the number of people a pupil can communicate with is extremely limited. Speech is a standardised mode of communication as the vast majority of pupils in our schools use English, and signing has various formal languages. However, where objects of reference are concerned it is a different matter completely.

What are objects of reference?

Objects of Reference (OR) are objects that have special meanings assigned to them, they *stand for something*, in much the same way as words do, whether spoken, signed or written.

OR need to be separated in definition from objects, as the OR need not have any features in common with what they represent, but derive their meaning through association. For example: a small toy bus is an object and may be used to represent going out on the school bus, but it is not an object of reference. The OR may be derived from the pupil's experience of the bus such as the seat belt or seat material; the pupil derives his or her own meaning. Imagine a pupil who is visually impaired and a wheel chair user and who may never touch or see the whole mini bus. How can they derive meaning from a toy bus? A class of eight pupils all using OR through deriving their own meaning from activities might have eight different sets of OR for their vocabulary. How do these pupils talk to each other? What happens when they move outside of class or to another class? The class is using eight different ‘languages’.

Within special education OR have predominantly been used to inform pupils of their daily timetable and to prompt the transition between activities, the OR being presented to the pupil. However, this does not constitute a communication system, as it is all one way. For OR to be used as a communication system they should be used in two way situations, enabling pupils to interact with others (family members, staff and peers) to ‘chat’, request activities and inform others of their needs.

The communication group needed to consider OR as part of the communication continuum, and how they would be used by our pupils, both as a communication system in themselves, but also as a stepping stone to what has been considered as more formal levels of expressive communication.

Historically objects of reference have not been seen as a formal mode communication. However, following the publications; *Planning, teaching and assessing the curriculum for pupils with learning difficulties* (QCA 2001) and *The National Literacy Strategy: Framework for teaching* (DfES 2001), OR have been referred to as tools to be used for reading and writing. If a pupil places an object, they are then making an intentional mark and **writing** in their preferred medium, which can then be read back. If the OR are presented to the pupil, the pupil is **reading** through their preferred medium – gaining information using their preferred medium. In this manner objects of reference are being used as common symbols shared among a wider community and therefore constitute a formal mode of communication (Rowland & Schweigert 1998). OR occupy a distinct place in the wider field of formal communication, offering a means of formal self-expression in the tactual domain.

> *“All children ….. need to be able to learn and play and develop alongside each other…”*
> The Rt Hon Charles Clarke (2004)

For children to do this they need to be able to communicate with each other, which they cannot do unless they are using the same language. As a special school, we cater for large numbers of pupils who are using OR and symbols and therefore we felt that it was our duty to provide the pupils with a system through which they can understand each other and so learn together.

Whole school approach to objects of reference

The communication group decided that the school needed to have a whole school approach towards the use of objects of reference (OR) as we needed to implement them as part of the school’s communication policy. Therefore, we had to give consideration to the following:

1. If OR are to be used as a communication system there needs to be some form of standardisation so everyone understands their meaning, and also so that they can be used throughout the pupil’s whole school experience (day to day and throughout the years). The use of OR can also be seen as part of the learning process and so should be able to be used as part of the progression for pupils onto pictures and symbols, etc.
2. For OR to have meaning their implementation should be led by the pupil, i.e. the OR used is decided upon by the pupil through the meaning or experience derived from the activity.

The communication group decided that pupils need to be able to develop their own OR, deriving their own meaning from activities, etc. However, the school would also develop its own vocabulary as a framework to guide the development of the pupils’ formal communication.

Kingsley Vocabulary

The communication group discussed the implementation of a ‘Total Communication’ philosophy in the school, through which all pupils have the opportunity to learn and communicate using whatever mode of communication they feel comfortable. Total communication also lends itself to the teaching of communication in a holistic manner considering the continuum of communication. The school has been fully signed up to individual learning styles and our pupils should also have the opportunity to develop their communication in the same way

Type of expressive communication	**Vocal**	**Gestural / visual (person based)**	**Gestural / visual (externally based)**	**Tactile / haptic**
Non-intentional	Cries in response to personal need	For example: *arches back in displeasure*	Looks at things	Touches things
Intentional	Deliberately cries / vocalises to show need	For example: *reaches out to be picked up*	Points to things	Consciously manipulates objects to communicate for example: *hands adult toy to play*
Symbolic	Makes personal utterances: for example *says 'mmmm' meaning 'hairdryer'*	Makes personal signs: for example *flaps hand for 'yes'*	Points at pictures Scribbles / draws	Uses Objects of Reference
Formal	Speaks (using words)	Uses conventional signs	Points at symbols / words Writes (print)	Uses Braille / Moon

(Ockelford 2002)

(visual – symbols / signing, kinaesthetic – signing / OR, auditory – speech).

The implementation of a whole school total communication strategy was not as straight forward as giving out banks of OR and symbol cards and putting OR on doors. As well as the production and purchasing of all the resources staff needed training in unfamiliar modes of communication. Their implementation of total communication needs a carefully planned approach with a lot of consideration towards how, when and where the different modes are to be used, and also with a great deal of thought into their purpose.

The communication group quickly decided upon the various formal modes of communication to be used: speech – English; signing – Sign Supported English, using adapted British Sign Language (BSL) as necessary for the physical needs of our pupils and used to support the English language (as we are talking about total communication) rather than using the BSL signing convention of language; symbols – Picture Communication System (PCS) symbols, as used with Clicker4 and Boardmaker programmes.

The communication group started by compiling a list of 'high frequency' words that pupils would want to use – "come here", "go away" etc and then considered each mode of communication (speech, signing, symbols, OR, photographs) and how they all link together in continuum of communication. Once the list was compiled, the task of producing the resources took place.

The Kingsley school communication group launched the high frequency vocabulary with training for parents and staff during the summer and autumn terms (2004) and resources produced by the group were in classes during the first half term of the autumn term. Assessment of the communication needs of our pupils was undertaken highlighting primary modes of communication and then whether the pupil needed a secondary mode to ensure understanding. This enabled resources and communication aids to be provided for classes (not solely for the pupil so promoting total communication) and training for staff in the various methods employed. Following whole school training delivered by Clare Latham (September 2004), communication boards and books (Latham 2004) have been introduced. The training also highlighted the use of a relevant core vocabulary (Latham & Miles 2001) appropriate to the level of language development of the child. Fortuitously the high frequency vocabulary developed by the communication group was very similar to the core vocabulary proposed by Latham & Miles. To aid the use of OR and symbols across the school, departmental teams have developed a consistent approach to making the resources available. Each class has a consistent 'communication area' so pupils who are able to do so independently can locate and access communication resources; communication trays are used to make OR accessible for pupils and staff training has increased their awareness to the needs of their pupils and the need for being responsive to communications and making the environment communication friendly. This has also been in addition to the availability and use of communication aids across the school (a whole other area for discussion!)

The communication group is at present developing an Areas Vocabulary for use in the school and producing "Tell Me" boards. The "Tell Me" boards will be sited around the school, including on the playground and accessible for use in toilets, to enable pupils who use symbols (including the high proportion of our pupils highlighted as users of speech but who need symbols to consolidate understanding) to communicate anywhere in the school. Consideration has also been given to pupils moving on to secondary school and we have started working with the school to which our pupils with more complex needs will be transferring. Pupils with communication difficulties will have communication passports in place, and all pupils (in the not too distant future when I get time to breathe!) will have communication profiles highlighting targets for the development of their communication.

The implementation of total communication is still in its infancy at Kingsley. However, some of the feedback from classes that have got to grips with the system has been extremely positive. The aim of the vocabulary system was to enable pupils to talk to each other and there have been instances of pupils with moderate and severe learning difficulties using OR with pupils who have PMLD. In one example a pupil has used objects to help peers with PMLD to make choices and express their needs. The introduction of a total communication philosophy has given pupils the opportunity to develop their communication skills, enabling them to use symbols and signs as prompts to communicate verbally, and for our pupils with more complex communication difficulties the scope to develop their language using OR, leading to photographs of the objects and developing the use of symbols. The work of the communication group, and the staff as a whole at Kingsley, will be ongoing to support the individual needs of our pupils and striving towards enabling all pupils being able to communicate with anyone they encounter, even if only to say "Go away!"

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Intensive Interaction : Some Practical Considerations

by Mark Barber, Ph.D, Consultant in Profound Intellectual Disability / Severe Communication Impairment and Intensive Interaction Coordinator at Bayside Special Development School, Moorabbin, Victoria, Australia

Intensive Interaction is the name given to an approach to developing the ability and desire to communicate and participate in social interactions. The approach was developed and is primarily used with people who experience profound intellectual disabilities. They might be described as having a high dependency on the interpretation of others to make themselves understood; a level of awareness of their own intentions which is low, or difficult to determine; a level of comprehension which is low or difficult to determine. They may have very limited or inconsistent ways of communicating which frequently lead to an ambiguity of meaning and indeed, may have acquired a tendency to acquiesce to the suggestions of others and an inability to contradict (another's) interpretation (Grove, Bunning, Porter and Olsson 1999) The approach is also "used as a means of developing interaction skills in people who are typically very…. withdrawn or who spend large amounts of time in….ritualised, self oriented behaviours". (Goldbart 2005)

In spite of its origins being clearly stated (Nind & Hewett 1994) as derived from developmental perspectives on learning, Intensive Interaction is firmly based in a 'normalisation' or social role valorisation set of values and beliefs, emphasising as it does, the central importance of valuing people for who they are.

The aims of Intensive Interaction

The aims of Intensive Interaction include to develop cognitive abilities including social cause and effect and predicting and exploring the behaviour of others; sociability, including the desire and ability to be with others, taking part in and initiating social contact and understanding the ways in which social encounters can be enjoyable; and fundamental communication abilities including eye contact, facial expression, turn taking and engagement (Nind & Hewett 1994).

Intensive Interaction is not characterised by the delivery of a regime of techniques or of specific content - rather, it could be termed a 'naturalistic' approach. The manner in which practitioners guide their learner's emerging communication is largely informed by a number of principles that are derived from the analysis of nascent social interactions in typical development.

Key Features

The key features of the approach include the creation of mutual pleasure and interactive games, being together with the purpose of enjoying each other; the skilled partner adjusting her/his interpersonal behaviours (i.e. gaze, voice, language use, body posture, facial expression) in order to become engaging; interactions flowing in time with pauses, repetitions, and the skilled partner blending their responses to the mood and preferences of the learner; the use of intentionality (the willingness to credit the learner with intentions) i.e. responding to behaviours as if they were requests or indicators; and contingent responding- i.e. following the learner's lead and handing over control of the activity (Nind & Hewett 1994).

Observation

A good period of observation is of paramount importance in Intensive Interaction, as to be able to engage the learner on their own terms requires the practitioner to recognise the learner's preferred locations, ambiences and modes of sensory experience (i.e. movement, sound, cadences). Observation should also identify to which environmental events the learner orients with interest as these may present valuable contexts for communicative exchanges. It is central to the practitioner's approach to be alert to opportunities that may arise that enable them to respond to and follow the learner, into coordinated joint attention or joint participation in a mutually acknowledged focus.

Observation should also identify any events or approaches that may be causes of anxiety or fear for the learner, so that they can be avoided.

The information collated in this period will be used to inform the practitioner's early attempts to engage the learner in initial exploratory encounters. Indeed the early work in Intensive Interaction involves developing a number of playfully ritualised routines that engage the learner. This is frequently most effectively accomplished by the practitioner assuming or reflecting some of the learner's characteristic behaviours. "We look for things that have meaning for the learner and using them, shift their attention from solitary space and activity to shared activity………we look at what they do and do it with them" (Caldwell 2002) Using behaviours or patterns of behaviour that the learner characteristically demonstrates, optimises the familiarity of the 'content' of the dialogue for the learner. This approach often apparently engages interest and curiosity when their own 'sensory language'(Caldwell 2002) is noticed occurring at a novel location. As Nind & Powell (1999) suggest, "practitioners should attempt to engage the (learner) with 'intrusions' that are within (their) existing behavioural repertoire or known pleasure"

Interaction

Once the practitioner has attracted the interest of the learner and has established some level of familiarity with and curiosity in their approach, the practitioner begins to explore the possibilities of engaging the learner in reactive dialogues, using features that the observation has suggested. It is central to these early interactions that the skilled partner demonstrates their intention to follow the learner's lead, effectively handing over control of the engagement and empowering the learner to control its duration and subject.

The practitioner continually monitors, reacts to and interprets the learner's reactions and behaviours to their presence, in a manner which demonstrates that the learner's actions have both predictable repercussions and social currency. Simply put, using Intensive Interaction, the skilled practitioner continually responds to the learner's behaviours, in a fluent manner, which is individualised to meet the idiosyncrasies of the learner. In a sense, the practitioner envelops the learner in a communicative context, so that no matter how the learner acts, the more skilled partner can shape their own response so that it facilitates a further opportunity for the learner to contribute. It is rather like a game of tennis between a novice player and a coach, where the supportive coach will always hit the ball back somewhere within the reach and comfortable stroke of the novice, wherever they are on the court.

While the choice of activities is controlled by the learner, the practitioner's role involves shaping the encounter to attract the attention of the learner to what might be described as 'interactive features' of the communicative process. Opportunities to engage in turn taking, bursting and pausing, imitation, anticipation and negotiation can be manipulated by the practitioner, so that although following their partner's choice of 'topic' (e.g. hand clapping, or vocal sounds) in a dialogue, the practitioner suggests communicative themes or directions. Mutual attention might be drawn to the introduction of 'anticipation' into a dialogue, by for example, the practitioner hesitating their contribution to an established burst-pause dialogue. This will disrupt the rhythm of the dialogue, and introduce a novelty or surprise that can be mutually recognised and revisited in later encounters. In a similar manner, hesitation at the end of 'build-up games' or 'frames', which lead the learner to expect a particular sequence of events, might be used to lead the learner into affectively signalling their expectation of the final element of the sequence. By acknowledging and acting on this affective response, the practitioner both draws attention to it and underlines its communicative significance.

As interactions evolve and become more established, and thus recognised, they become increasingly reciprocal, allowing the practitioner to hand over progressively more control to the learner.

Roles

The role of practitioner as 'respondent' rather than 'initiator' of social interactions frequently promotes tensions between practitioner's self image as a provider of knowledge and guidance, and the acknowledgement of the learner as a partner and decision maker. However, it is certainly uncontroversial to concede that the quality of a learner's attention is substantially greater when focussed on events of their own choosing rather than on events chosen by someone else (e.g. Warren & Yoder 1998).

While it is a central tenet to the approach that the learner and their contribution are controlling influences within interactions, there is a practitioner agenda, but within Intensive Interaction, "it relates to a way of operating rather than a content to be delivered" (Nind & Powell 1999). The practitioner is there to extend the situation's communicative potential through rich interpretation and empower the learner to explore communicative interactions

Techniques

It was stated earlier that this approach is not characterised by the delivery of specific techniques. However, interaction with learners, whose perceptions of environmental responses may be impaired, distorted, disrupted or oriented to internal focuses that are not within the practitioner's influence, requires the guiding partner to rethink their palette of responses to draw the learner's attention to their presence in the interaction.

Within an interaction, no matter how idiosyncratic the behaviour, Caldwell (e.g. 2003) advises, it needs to be interpreted as part of who the learner is and as having potential for interaction. However, it is also stressed that the learner doesn't set the whole agenda regardless of the practitioner – the approach is one of mutuality and interaction. Successful practitioners of intensive interaction manage to combine "spontaneous responding with extreme sensitivity to the idiosyncratic needs and behaviours of the learner, while intellectualising the developmental principles being applied" (Hewett & Nind 1998). This enables what Caldwell (2003), describes as 'a wandering state of mutual response' to develop "……active in the sense of awareness and response, but passive in the sense of floating rather than swimming."

Simply responding by imitation, or repeated turn taking, can over time lead to the emergence of loops of activity, where the practitioner's contribution can become assimilated into the cycle of a closed stereotype, rather than maintaining a communicative balance. This can usually be avoided by the introduction of new, slight variations of the familiar behavioural features that the learner favors, into the exchange. This imbalance might also be avoided by some level of environmental manipulation, e.g. by the practitioner prominently placing of a significant or favoured object close by.

There is a lot of useful information available on ideas that practitioners might use to engage mutual participation in an interaction (e.g. Caldwell 1998; 2003, Nind & Hewett; 2001). These include for example 'echoing' a behaviour, where the practitioner responds using the nature or timbre of a behaviour, in a sensory mode other than the one the learner is using; for example tapping out the rhythm of the learner's vocal sounds on a part of their body where they accept touch. Practitioners might adjust this to 'reflect' the pauses *between* their partner's behaviours, if they feel that their echo-ed contribution is being absorbed into a stereotypic loop of sensation.

Recording

It is the issue of recording and prediction of progress that frequently causes the most tension among practitioners. This is especially so for those working in educational settings, where the effectiveness of an approach is often measured in terms of linear progression along hierarchies of cognitive or behavioural checklists. However, it can also be argued that horizontal progress, or the demonstration of understanding or strategies across more varied applications, is equally valid (e.g. QCA, 1999).

Recording progress presents many difficulties. It is always easier and certainly more tempting to record the demonstration of performed skills or 'content' than to measure a learner's involvement in the more important arena of 'process'. However, it is important to record interactions to enable team approaches to develop as well as to ensure that the important features of a previous encounter with a particular learner are more likely to be remembered for the next exchange.

While conventional recording tends to be dominated by ideas of recording achievement or skill application; noting the learner's level of involvement may present a more meaningful method for describing and recording progress, especially in the context of Intensive Interaction. '*The Framework for Recognising*

Conventional interventions	Intensive Interaction
Conventional interventions typically begin by assessing the learner to identify what skills are problematic, or which areas of the learner's performance (as assessed against a checklist or curriculum) indicate intervention	Using Intensive Interaction, observation is aimed at identifying strengths and preferences, so that these become the contexts for communicative encounters.
Conventional styles of intervention and teaching are characterised by the teacher or therapist deciding on a predicted outcome or objective	Intensive Interaction is characterised as open ended – the outcome of encounter is not predicted or 'driven' towards
The practitioner conventionally leads & controls, or drives the interaction : engaging the learner in a (planned) teaching session	Using Intensive Interaction the practitioner makes themselves available for social activity. The activity or focus of the practitioner is not dominant. Termination of the interaction is under the learners control
The teacher/practitioner/ therapist usually leads by providing the focus or interest, attracting learner's attention into joint focus (usually an object)	Using Intensive Interaction the practitioner looks for and *responds to* the learner's focus of interest by demonstratively joining in with it.
Conventionally, the practitioner/teacher/therapist has control over place, subject and reward associated with experience	Using Intensive Interaction these depend on the preferences of learner
Stereotyped, self involved, or ritually organised behaviours are conventionally considered 'inappropriate', they are frequently the focus of intervention aimed at extinction	Using Intensive Interaction these patterns of behaviour are seen as important, frequently indications of interest, that are significant to the learner
Teaching and therapy interventions frequently focus on teaching new skills or protocols	Using Intensive Interaction practitioners should attempt to engage the learner with 'intrusions' that are within their *existing* behavioural repertoire or known pleasure, horizontal progression *across* contexts is as valuable as vertical progression along hierarchies

Attainment' (Marvin, 1998), which underpins the '*P-levels*' or ' *Performance Descriptors'* that structure the Qualification and Curriculum Authority's documents on *'Planning, Teaching and Assessing the Curriculum for Pupils with Learning Difficulties*' (QCA, 1999), presents an excellent model for this purpose. The hierarchy describes a progression in the manner in which the emerging involvement of the learner in communicative experiences might be marked. The following descriptors from Firth's (2004) framework, used in adult services in Northern England, retain the spirit of the QCA framework but have distilled them for brevity.

Encounter: The student or client is present during an interactive episode but without any obvious awareness of its progression: *e.g. a willingness to tolerate a shared social atmosphere is sufficient*

Awareness: The student or client appears to notice or fleetingly focus on an event or person involved in the interactive episode *e.g. by briefly interrupting a pattern of self-absorbed behaviour, movement or vocalisation*

Attention and Response: The student or client begins to respond (although not consistently) to what is happening in an interactive episode, *e.g. by showing signs of surprise, enjoyment, frustration or dissatisfaction*

Engagement: The student or client shows consistent attention to an interactive episode presented to them: *e.g. by sustained looking or* *listening, or repeatedly following events with movements of their eyes, head or other body parts*

Participation: The student or client engages in sharing or taking turns in a sequence of events during an interactive episode, *e.g. by sequencing their actions with another person, or by passing signals repeatedly back and forth*

Involvement: The student or client makes active efforts to reach out, consistently join in, or even comment in some way on the interaction, *e.g. by sequencing their actions* ***and*** *signing, vocalising or gesturing in some consistent and meaningful way*

Student/client Initiated Interaction: The student or client independently starts an activity (that cannot be described as repetitive or self-absorbed behaviour) and engages another person in the activity with social intent.

While the framework does not address the notion of predicting progress, it is quite possible to record an impression of the involvement that the learner demonstrates and, over time, to trace its progression as the subsequent interactions occur.

Following an encounter, practitioners record their impression of the 'peak' or most significant phase of the interaction, using the 'best fit' descriptions indicated in the framework, along with a short description of both the context and the learner initiated contribution that resulted in this impression.

This framework is currently being used at Bayside Special Developmental School in Moorabbin, Victoria, where it has proved useful to video interactions between staff and students so that moderation can be achieved within in-house recording among involved staff. This enables improved levels of reliability to be achieved across the school, as well promoting staff training in analyzing their interactive effectiveness, how they might progress and a recognition of the processes being encouraged in the interactions. Considering our interactions in this way is providing invaluable insights into pupil communication and it is also developing a more flexible palette of staff responses. Most importantly is the increase in practitioner awareness of the manner in which learners can be assisted to explore communication and empowered to control interactions.

Progress

Investigation of Intensive Interaction has so far been largely dominated by small studies, carried out by practitioners in service settings (e.g. Elgie & Maguire, 2001; Fisher & Watson, 1997; Irvine, 2001; Kellett, 2003). Indeed it is practitioner experience in a range of settings that is generating the progressively growing interest in the approach. While there is a growing body of publications making reference to and discussing its use, there are a number of confounding issues to deal with, not least of which is to arrive at a definition of what meaningful 'progress' actually is for learners with this level and complexity of intellectual disability. Debate is also needed to decide on the most useful focus for more structured investigation; e.g. whether it is the learner's communication which progresses, or the practitioners observation skills which become more sensitive and attuned to the learner. However, because of the variety of disabilities associated with these learners, and the implications of multiple disabilities interacting with each other, this population are renowned as being difficult to standardize or homogenize into the uniform groups necessary for large scale study.

Whether in educational or adult settings, the long term aim of practitioner's efforts with their clients is the same - improved quality of life. Adopting Intensive Interaction may or may not prove to be advantageous in terms of measurable skill acquisition over other approaches but it does not aim to be. Neither does it attract the financial backing of associated with other approaches that purport to generate measurable progress in learners with complex intellectual disabilities. Intensive Interaction is centrally a values driven approach. Adopting it leads the practitioner to realign their perception of intellectual disability from one of a learning deficit, to that of a range of potentials and opportunities: The learner is valued for who they are, rather than for who they can be trained to be.

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Planning Involvement in a School Community for Children with Profound and Multiple Learning Difficulties

by Rob Ashdown and Alison Harland
St. Luke's Primary School, Scunthorpe

A Brief History

St. Luke's Primary School is a day special school in Scunthorpe, North Lincolnshire. Currently, there are just over one hundred children on roll aged from 3-11 years with moderate, severe and profound learning difficulties. 15 of these children have profound and multiple learning difficulties (PMLD).

The school was opened in September 2002 following reorganisation by the North Lincolnshire LEA of its two special schools. Both of the former special schools were successful schools but had extreme accommodation difficulties. Reorganisation was a long drawn-out process starting in early 1997. There were five years of considerable uncertainty for staff and parents, although the children themselves were remarkably resilient throughout. The process was helped by the excellent cooperation and goodwill shown by all parties but was hindered by frustrating setbacks and vicissitudes.. However, the two new schools, St. Hugh's Secondary School and St. Luke's Primary School, are now settled into very good new buildings. Pleasingly, and reassuringly, both have had good reports following Ofsted inspections in 2004/05.

The Buildings

From the outset all of us – staff, governors, parents and pupils - were involved in some way in the design of the new buildings. As regards the provision for pupils with PMLD, we had a significant influence upon the design of the whole building as well as the specialist provision through our close work with the architects. We may not have got everything we wanted due to prohibitive costs but we certainly got everything that we felt was essential.

The building does provide all of the facilities required to deliver a high quality education. A key 'selling point' for the new school from the outset was the pool for warm water activities which are essential to the physical development programmes of for pupils with physical disabilities. Another is that the building at is all on one level and does not present access problems for wheelchair users. The corridors have a good width and the walls have been protected with brightly coloured 'bumpers' so that it does not matter when children do not steer properly their mobility aids or wheelchairs. Even so, we have had to tape plumbers' lagging to some mobility aids to reduce damage to the building. Steering only comes with practice!

The school has separate PE and dining halls so that there is full-time access to a hall for, say, a music and movement activity. Each classroom has a ceiling mounted tracking rail and hoist for the safe moving and handling of children with physical disabilities so that they can have regular changes of position for their physical well-being and so that they can access a range of activities. The provision of this moving and handling equipment has had a dramatic benefit for staff who often experienced back problems from their work in the old school building. There are specially equipped hygiene areas nearby and a lot of thought has gone into the planning of the layout of these. The various specialist teaching areas, e.g. cookery and art rooms, incorporate such features as adjustable height sinks and tables to accommodate children who are in standing frames or wheelchairs. The sensory garden in the school's inner courtyard has raised beds created using log rolls and adjustable height horticultural benches for gardening activities.

Access to the Curriculum

If a child has physical disabilities, we aim to teach mobility skills in the classrooms and corridors.

Each classroom has a ‘quiet room’ and other areas which can be used for physiotherapy and developing sensory perception and exploratory skills using specialist equipment and computers.

A whole school curriculum had to be established for the new school. Subject leaders produced policies and long-term plans and wrote units of work, producing the units of work in advance of each term that they were required. This process is still ongoing and will not be complete until the end of 2006/7. Curriculum development has required an enormous commitment of school funds both for non-contact time for subject leaders to minimise the burdens of their task and for providing appropriate educational resources. All units of work are being evaluated through a rolling programme. It is plain from this evaluation that a lot of work still has to be done to ensure that teachers have the guidance and resources that they require to ensure that all pupils can be meaningfully involved in all activities in their classroom. This is not an easy task when a teacher has to teach and meet the personal needs of 10 or 12 children with the whole range of special educational needs. We do want to see all children involved in classroom activities and none marginalised.

For this reason, a decision was taken that a member of the school’s new senior management team should be a lead specialist in teaching pupils with PMLD. That person is Alison Harland who is an assistant head with a responsibility for supporting the staff throughout the school in developing best inclusive practice and using the specialist facilities and resources available.

In recognition of the difficulties faced by teachers in teaching children with a much wider range of special educational needs than they had experienced hitherto, another early decision was that, for a transitional phase of several years, there should be a specialist class for pupils with PMLD at Key Stages 1 and 2. We are not happy with having to take this decision but we are doing all we can to move towards full inclusion in a measured way. We do have a system which allows us to identify objectively which children need access to the specialist class if they cannot cope with the ordinary classroom environment for any activities. The same system is used to identify which children need access to the ordinary classroom. Also, we have systems for auditing staff professional development needs to inform the school’s continuing professional development plan. Of course, it is envisaged that eventually all classes will have sufficient staff with the necessary skills and the necessary physical resources to enable the specialist classroom to become a resource base offering teaching and assessment activities and physical and human resources that simply cannot be provided in the ordinary classrooms.

Alison Harland is also responsible for the implementation of the MOVE programme throughout the school and the school has invested heavily in a wide range of costly equipment to support it. MOVE stands for Mobility Opportunities via Education (for more details visit the MOVE Europe website at www.move-europe.org.uk). The programme combines therapy and education to most effectively teach functional activities and, therefore, MOVE gives the children the opportunity to take greater control of their lives. MOVE uses a top down approach that focuses on activities that people are motivated to achieve, rather than what they can not do. In an initial assessment with the individual’s family, goals are determined and a time frame to achieve these goals is set. These goals are then broken down into activities within which manageable and achievable targets and are set. Some specialised equipment is used on the programme as a tool for learning new skills.

The use of the MOVE programme has improved greatly the life chances and the education of

children who have significant physical disabilities. It has given children the opportunity to sit, stand and walk and to explore actively their environment. These activities have stimulated their physical development since they help improve breathing, circulation and muscles and promote bone density and good posture. With the full cooperation of parents and a dedicated group of staff (teachers, teaching assistants, physiotherapists and occupational therapists), very good practice has become firmly established. Independently, the report on St. Luke's Primary School from the Ofsted inspectors states that the MOVE programme is a great strength of the school curriculum and that the MOVE programme is very successful for pupils here.

The Mobility Trail

The pupils need to learn new skills of walking up and down slopes and steps and of walking on uneven ground and different surfaces in preparation for moving around the wider community. However, the school was deliberately built on one level without any steps or ramps and all floors are smooth and hard to allow for ease of propulsion of wheelchairs and mobility aids.

We had long considered constructing a mobility rail but had a frustrating wait until we had moved into our new premises. Also, the money for the reorganisation project did not extend to building a mobility trail so we had to find the money. We were helped by donations from the local community and through the efforts of a school governor, Barbara Abbey, who secured a large grant from a charitable body called Enventure. Matched funding was also available through the LEA. Alison Harland worked closely with Peter Beschizza, the council's landscape architect for the special schools project, and Mike Farnsworth, a contractor, to develop a design for the mobility trail that would incorporate a wide range of the different gradients and surfaces found in the local streets, shopping centres and parks. Peter and Mike had quite a struggle sourcing some of the materials and setting in concrete, literally, the various surfaces so that they did not present transitions of surface types and levels that were too extreme. Ramps, kerbstones and steps were incorporated into the trail along with bollards, a gate, gullies, gutters, grids, cobbles, wooden decking, stepping stones and a range of paved surfaces. Tarmac was used as infill between the different surface areas and to provide one continuous path that can be easily negotiated by beginners. One mistake was to incorporate gravel – it simply is such fun for children to kick or throw it around! The gravel was intended to provide a yielding surface so we are now looking to replace it with playground safety surfacing to give a similar yielding sensation underfoot.

The mobility trail offers pupils with sensory and perception difficulties **time** in which to gain confidence in walking on different surfaces and solving the problem of how to get from one area to another in a safe and calm manner. Those pupils on the MOVE programme can now meet these challenges in a safe and constructive way that will offer them the means to expand and build on newly acquired skills, be it independently, assisted by an adult or independently using a Rifton Pacer or a rollator. Those pupils who have to ride in a wheelchair will also have the opportunity to experience being pushed over different surfaces, around obstacles and up and down kerbs. The mobility trail will also benefit the wide range of pupils in the school who have coordination difficulties even though they may not have physical disabilities.

During this coming Autumn and Winter a range of shrubs, trees and herbaceous plants will be planted to enhance the mobility trail. They have been chosen for their attractiveness to local wildlife, their resistance to the predations of the local rabbits and for their sensory properties that give smells and textures for the children to explore. This will make the trail an exciting, inclusive learning environment for all of the pupils.

Staff professional Development

Developing staff expertise throughout the school is essential if there is to be meaningful involvement of pupils with PMLD. In this context, it is worth noting that as part of the process of special school reorganisation, the council produced new job descriptions for teaching assistants (at several levels). The union representatives, personnel officers, head teachers and representative support staff from the special schools worked well together in arriving at job descriptions for support staff that accurately reflect what they do. Salary grades were independently determined once the job descriptions had been produced and for the majority of staff the new posts attracted a significantly higher salary. The job description for one of the senior levels of teaching assistant recognises that they alone may carry out activities requiring specialist knowledge and expertise (including physiotherapy and some types of invasive care activities). Therefore, it has always been critical that there has been sufficient of these relatively expensive teaching assistants so that they are available in all classes where there are pupils who require their particular skills and knowledge. Alison Harland has developed a committed team of teaching assistants in her own class who have considerable knowledge and skills that enable them to meet the needs of the pupils and also to support the professional development of staff elsewhere in the school as regards training in the MOVE curriculum, moving and handling, and techniques to help with feeding, communication and curriculum access. Over time, the planned training opportunities for the whole this group of teaching assistants will support the goal of the wider inclusion of all pupils in the ordinary classrooms.

The school as a resource centre

There was a very special occasion at school on Friday 24th June to mark the launch of St. Luke's Primary School as a MOVE Regional Centre. 80 invited guests and a number of children from both of North Lincolnshire's special schools and adult learners with disabilities attended. The quality of the MOVE programme is such that the MOVE Europe organisation has officially recognised that the school is well-placed to provide a lead on the development of MOVE throughout North Lincolnshire and, eventually, other parts of the region.

North Lincolnshire LEA is also supporting the development of St. Luke's Primary School so that it can act as resource centre to other schools and make regular contributions to mainstream schools that support the development of their own inclusive practice. The LEA agreed to fund a teacher to support outreach work. She and other staff in the school have a range of skills and knowledge which will benefit many schools and pupils. For instance there are staff who are trained to do risk assessments in relation to moving and handling of pupils with physical disabilities. Other staff have other skills in relation to the use of ICT and communication systems. So skills learned from working with children with PMLD are benefiting a larger group of children with physical disabilities in ordinary schools. Which is a nice note to finish on because it shows the importance of these children in our school community. In their various ways they have made us develop skills and knowledge that will be useful to many others in the wider community.

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Postcard from Abroad

MALTA

by George Borg, Special Schools Network Co-ordinator

San Miguel School is one of the special schools in Malta. It caters for the education of 47 children in the age range between 3 and 19 years. All of the pupils have severe learning difficulties and physical and/or sensory disabilities. 83% of the school population function up to or below P level 3.

The school opened in 1989 and has had major refurbishments since then. It is a single storey building which was originally one of the English military buildings on the island. The school is named after Saint Miguel Febres Cordero (1854 – 1910) an educator and priest from Ecuador.

The school has six well-equipped classrooms, one large hall, a ball pool and soft play area, a multi-sensory room and an ICT room equipped with latest technology. The school has a hydrotherapy pool, which also serves as a leisure pool for pupils and their families, and staff are trained in the Halliwick Swimming Therapy.

The staff consists of a Head Teacher, six class teachers and three or four teaching assistants per class. There are two full-time nurses and regular visits are made by a doctor, dentist and other health professionals. Three physiotherapists and three speech therapists visit the school twice a week and have access specially equipped therapy areas. The physiotherapists also direct the hydrotherapy sessions with support from school staff.

The school follows the National Minimum Curriculum. The school is a member of the UK organisation EQUALS and we work on the PACE 2 document as a means of assessment and use the EQUALS Schemes of Work for our curriculum. The staff development programme has included input from educators from the UK. Peripatetic teachers for music, art, drama and PE also contribute to the educational activities.

We have links with mainstream schools for inclusion and with other special schools. Some pupils with PMLD visit the school twice a week to make use of the facilities and expertise available in the school.

For further information you may visit the school's website: http://schoolnet.gov.mt/sanmiguelschool/

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Research

Use Of An Assessment Tool To Record Episodes Of Distress In People with Severe Communication Problems

by Beckie Whelton, St George's, University of London Department of Mental Health (Learning Disability)

As a Parent or a Carer, I am sure you can recognize the following situation..You are caring for someone with learning disabilities who has limited verbal communication. You know there is something not quite right. You go with them to the doctor's, or a specialist, and you are not listened to.

It can be difficult to know when a person with learning disabilities is in pain or distress, especially when the person cannot say so in words or signs. If you know the person well you can often tell be the way they look or sound; but it can be hard for you as the carer to make sure that other people, such as hospital staff, understand the person's very individual way of communicating. Sometimes, nobody knows that the person is in distress, with the result that nothing is done to help.

In an attempt to overcome this problem, practitioners at Northgate Hospital and St Oswald's Hospice have developed an assessment tool to help staff and carers identify episodes of distress in people with communication problems associated with their learning disability. It is called the "Disability Distress Assessment Tool" (DisDAT). On the DisDAT form, you can record what the signs and behaviours are for the person when he or she is content, and the signs and behaviours that mean distress, for example, facial appearance, body posture, or sounds. After this is recorded, a monitoring sheet is used to record whether any of the distress signs have happened on each day. For further information about the DisDAT and background on why it was developed see Regnard C, Matthews D, Gibson L, Clarke C, Watson B. Difficulties in identifying distress and its causes in people with severe communication problems. *International Journal of Palliative Nursing,* 2003, 9(3): 173-6.

There is clearly a need in this area. You may wonder why the DisDAT isn't already widely used. The answer is simple. The tool has not been sufficiently tested yet. In a world of evidence based research, proof is needed before a tool such as the DisDAT can be accepted into established working practices. Therefore, we are conducting a study at St George's, University of London, Department of Mental Health (Learning Disability).

The purpose of our study is to test DisDAT. Our aims are to see if the assessment tool works and if it is possible to pick up distress in people with communication problems using DisDAT. We are planning do a larger study to test DisDAT properly, but first we need to conduct a pilot study to find out the best way to do this larger study. If the larger study shows that the DisDAT really does help staff or carers to identify distress in people with communication problems, then DisDAT can be widely distributed and used by staff caring for them. Equally, if the tool turns out not to be useful, we may be able to suggest ways to change it so that it works better or is easier to use.

We are currently carrying out the pilot study with 20 people in the London area who are carers looking after a person with severe communication difficulties. To be included in the study the individual may or may not be able to communicate verbally, but must be UNABLE to communicate their likes and dislikes in detail, unable to qualify, specify and/or indicate opinions. The Pilot Study is due to be completed in December 2005.

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What needs to happen to get day opportunities right for people with learning disabilities

The Foundation for People with Learning Disabilities and the Norah Fry Research Centre are starting a programme of work to evaluate what contributes to and hinders the successful provision of employment opportunities and community-based day activities for people with learning disabilities.

Having a good day? has been commissioned and funded by the Social Care Institute for Excellence. Evidence will be gathered through a research review, visits to services, and regional workshops which will involve people with learning disabilities and family carers.

The project team are keen to hear from people who know of unpublished evaluations of community-based day services, employment schemes, social firms, learning and leisure projects serving people with learning disabilities from across the UK; services considered to be delivering 'good' models of community-based support that help people with learning disabilities to do the things they want to do; and projects working in mainstream community settings with people with learning disabilities from ethnic minority communities, and those who need high levels of support.

Barbara McIntosh, Co-Director of the Foundation for People with Learning Disabilities, says: "The research will assist services to manage and achieve the changes required by the Valuing People policy agenda. It will also be used to develop a practice guide to inform day service modernisation strategy and implementation, demonstrating some of the steps that can be taken to achieve successful employment and community-based day opportunities for people with learning disabilities."

The evaluation will produce a final report in February 2006.

People who would like to contribute materials or ideas, or who simply want to know more should contact Angela Cole on 01621 869340 or email angela.cole11@virgin.net

Alternatively write to Angela Cole at The Foundation for People with Learning Disabilities, 9th Floor, Sea Containers House, 20 Upper Ground, London, SE1 9QB.

The editor of the **Summer edition** of PMLD LINK is

Julia Dixon
‘Early Years’

The copy date for all articles, information and news for the Summer issue is the 1st June 2005 and the focus is on ‘Early Years’.

Please send contributions to:

Julia Dixon
The Lodge
Willow Bank
Somersal Herbert
Nr. Ashbourne
Derbyshire DE56 5PD
Tel: 0121 303 1790
Julia.dixon@staffordshire.gov.net

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).

Adults with Learning Difficulties in England 2003/04

This report presents the outcomes of a survey carried out on behalf of the NHS Health and Social Care Information Centre by BMRB Social Research (a research company). You can listen to and download copies of the summary report from www.friendlyreports.org.uk. The main report can be easily downloaded.

Between July 2003 and October 2004 the research team interviewed 2,898 people with learning difficulties who were at least 16 years old. In practice, a support person was present in three out of four interviews, although the person with learning difficulties answered most of the questions in just under half of the interviews. It is not clear how many of the interviewees were people with PMLD.

The report highlights the relatively high degree of social exclusion experienced by people with learning difficulties and just a few of the headline results from the survey show graphically how much more needs to be done if the Government's avowed aims for improving the life chances of disabled people are going to be achieved. For instance, only one in six people of 'working age' actually had a paid job; people with learning difficulties were more likely to live in poor and deprived areas; nearly one in three said they did not have contact with friends; half of all adults with learning difficulties were still living with their parents; one in ten were living with other relatives; two out of three people in supported accommodation had no choice over either who they lived with or where they lived; over half said someone else decided how much money they could spend each week; under one in five were receiving Direct payments; only about one in thirty regularly attended self-advocacy groups; and nearly three in four people went to a special school.

The survey showed that people with learning difficulties are more likely to be poor or living in a poor area; these people are more likely to be living in unsuitable accommodation and have less privacy as result.

People with high individual support needs (sic) are more likely to not have gone to a mainstream school, not to be taking any post-school course, not to receive Direct Payments and not to have control over their money. They are more likely to feel helpless and lack confidence. They have a limited opportunities for friendships and contacts outside their home.

This is the first time that a survey has been done in England where the interviewees have been adults with learning disabilities. It serves to show that they simply do not have access to many of the experiences and resources that are regarded as important by the rest of us.

For more information contact:

Online: www.ic.nhs.uk
e-mail: equiries@ic.nhs.uk
tel: 0845 300 6016

PMLD Network Forum Digest March 05 – November 05

Day opportunities, community based activities
More discussions on concerns about the lack of planning/ consultation/ appropriate opportunities / resources /understanding of the needs of people with profound and multiple learning disabilities. Also questions about how to provide community based day opportunities for people with profound and multiple learning disabilities. Issues around quality of replaced day opportunities and changing facilities.

Definition
Debate about the need for a comprehensive definition to help people understand who we are talking about. Some members of the PMLD Network Core group are developing a definition which will be available soon.

Transition
Sharing experiences of transition. These were mainly about how difficult and frustrating the process is. www.thomascharlestrust.org a charity dedicated to transition needs of young adults with profound and multiple learning disabilities.

User parliament/user involvement
Question about user parliaments and people with profound and multiple learning disabilities‘ involvement. Suggestion to look at www.speakingup.org in Cambridge who have produced a video.

1:1 carer
Having got funding for a personal assistant how to find the right person?

- One family advertised locally and sent a letter to applicants about their daughters needs and the family.
- For a report on developing a PA; go to http://www.skillsforcare.org.uk
- Check your local independent living centre and check if your LA offers a service to support you.

Use of sedation versus general anaesthetic
Discussion on the use of general anaesthetic for intrusive medical procedures. Is it abusive not to use a G.A. if due to an inability to understand what is happening the procedure will be traumatic for the individual?

Intensive interaction
Discussion about the use of intensive interaction to interact and communicate with people with profound and multiple learning disabilities on their terms. Mentions Phoebe Caldwell and her books/ videos available from www.jkp.com also Dave Hewitt www.**intensiveinteraction**.co.uk.

Parents experience of LEAs

Sharing experiences, which were mainly bad and very frustrating for parents. Children need a very tight statement. Training courses for parents www.nwtdt.com.

Presence at meetings

Discussion about the appropriateness of people attending their meetings. Views about it being tokenistic and boring for some people. The need for it to be an individual decision about what is right and meaningful for that person.

Video consent

Question about videoing at day centre led to consent issues. Mencap will be producing some guidelines which will be available on www.mencap.org.uk/pmld.

Holiday accommodation

Sharing of ideas for suitable holiday accommodation. Here they are;

- Bolton Carers Support, for Breaks Brochure. 01204 363056 10am to 1pm, 2pm to 4pm Mon to Fri.
- Wingate centre in Cheshire http://www.holidaycare.org.uk/ telephone 0845 124 9971
- The Learning Disability Helpline has a holiday resource pack, it has details of holiday providers throughout the UK. If you contact the helpline they will be able to send a pack out to you. The number is 0808 808 1111 or email helpline@mencap.org.uk.
- We have been several years to Tenby and stayed in Harriet's House, one of the Trust properties
- http://www.goodaccessguide.co.uk/leisure/index.php
- The Jane Hodge Resort Hotel (Trerhyngyll Cowbridge Vale of Glamorgan CF7 7TNTel: 01446 772608 Fax: 01446 775831) near Cowbridge in South Wales
- Churchtown in Cornwall (Outwards bound activities available)
  Lanlivery BODMIN Cornwall PL30 5BT Tel: 01208 872148 Fax: 01208 873377 E-Mail: churchtown@saqnet.co.uk
- Calvert Trust on Exmoor www.calvert-trust.org.uk
- Netley Waterside Hotel in Southampton, www.vitalise.org.uk
- http://www.shu.ac.uk/services/cis/shucan/rdis/index-hols.html
- Felbury House Activity Centre in Dorking
- http://www.clynfyw.co.uk

The PMLD Network discussion forum (www.pmldnetwork.org) is run and maintained by the Foundation for People with Learning Disabilities, 7th Floor, 83 Victoria Street, London SW1H 0HW. Tel. + 44 (0) 20 7802 0316. Fax. + 44 (0) 20 7802 0301. Email: nmorris@fpld.org.uk Website www.learningdisabilities.org.uk Registered Charity No: 801130 Company Registration No: 2350846

Are any people with profound and multiple learning disabilities involved in 'user involvement initiatives'?

I would like to know if anyone has any examples of people with PMLD being involved in any of the many initiatives that are aimed at enabling people with learning difficulties to speak up about what is important to them.

I am interested in personal experiences or observations as well as any reports or research. Examples could be on a small scale such as one person who has got what they wanted from a service because they were included in something like a consultation or service evaluation. Or, it could be on a larger scale like two or three people with people with PMLD speaking up at a Partnership Board.

You may be thinking: well how would they do that? And that is exactly why I am asking this question. How *would they do that*? I know there are lots of ideas about how participation for this group could happen in theory e.g. building relationships, spending time, providing skilled advocacy, ensuring appropriate communication technology etc. But where is it happening in practice?

What I have found so far mostly focuses on how people with PMLD participate in decisions at the **individual** level. Some research reports on involvement of people with learning difficulties (without always stating anything about relative abilities) in decision making about policy and strategic issues. But I have not found yet many examples of research on the involvement of people with PMLD in policy and strategy; except to note their exclusion

I would be very interested to hear your examples and your views on this issue.

I plan to feedback my findings to you and wider audiences in the future. Thanks.

Paul Robson
Centre for Institutional Studies
University of East London
p.robson@uel.ac.uk

Websites

Organisations Mentioned in this Issue
Department of Health : www.dh.gov.uk
Foundation for People with Learning Disabilities ; www.learningdisabilities.org.uk
Jessica Kingsley Publishers : www.jessicakingsley.co.uk
National Association for Special Educational Needs : www.nasen.org.uk
Norah Fry Research Centre: www.bris.ac.uk/Depts/NorahFry
NHS Health and Social Care Information Centre: www.ic.nhs.uk
PAMIS : www.dundee.ac.uk/pamis
Qualifications and Curriculum Authority : www.qca.org.uk
Shared Care Network : www.sharedcarenetwork.co.uk
Social Care Institute for Excellence (SCIE) : www.scie.org.uk
Social Care Online: www.scie-socialcareonline.org.uk

Reviews

Title: Enhancing Self Esteem: A Self Esteem Training Package For Individuals With Disabilities

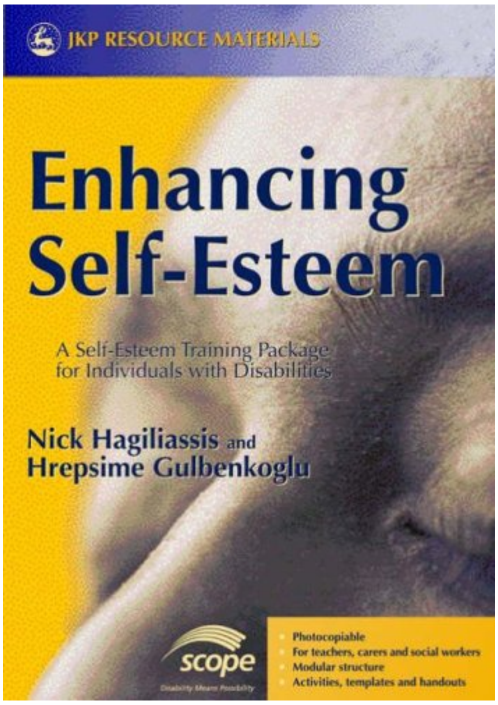
Authors: Nick Hagilassis and Hrespsime Gulbenkoglu

Publisher: Jessica Kingsley Publisher

ISBN – 1-84310-35-2

Pub Date: 2005

Price: £29.99



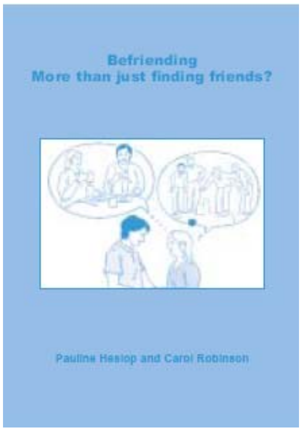
The purpose of this book is to provide a training pack for use with people with *'mild intellectual disabilities and/ or severe communication impairment'*. It is structured as a series of 10, two hour sessions, each aimed at a specific aspect of building self esteem.

Facilitators for the work would need few resources apart from the text and the level of detail given would suggest that anyone with sufficient experience working with this client group could use the material.

The use of pictures, photos and pictographs throughout will no doubt facilitate access to the material for a much wider range of people. The work is also carefully structured within each session: each begins with some fairly simple ideas and activities and moves to the more sophisticated concepts as the session progresses. I think the main difficulty of the approach lies here - this is touched upon by the authors in the introduction. If group members have receptive language difficulties as well as expressive challenges, understanding the (sometimes quite abstract) issues involved in the work will be problematic. Groups will need to be chosen very carefully and the less able individuals supported quite extensively.

Whilst the text does not present any new approaches to the topics covered, bringing this material together into one text is very helpful and will serve as a good basis for work on self esteem with people with mild intellectual impairment.

Reviewed by
Dr. Margaret Anderson
Learning Disability Lecturer
Thames Valley University



Title: Befriending. More than just finding friends?

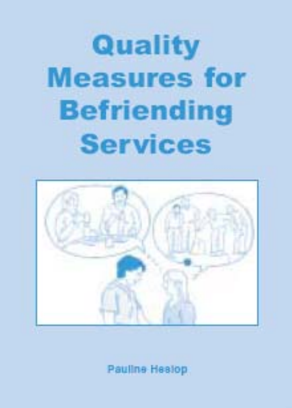
Pub Date: 2004

Authors: Pauline Heslop and Carol Robinson

Publisher: Shared Care Network

ISBN : 1-874291-17-9

Price: £13.95



Title: Quality Measures for Befriending Services

Author: Pauline Heslop

Pub Date: 2004

Publishers: Shared Care Network

ISBN: 1-874291-22-5

Price: £ 12.95

Both publications may be bought together for £20.95

In the first of these books Pauline Heslop reports a research project looking at seven befriending schemes in England. Although these sort of schemes, appear to be very popular, little is known about their effectiveness. So three organisations, Shared Care Network, the National Association of Adult Placement Services and Norah Fry Research Centre were involved in carrying out research in this area.

A range of services for adults and or children with learning disabilities were considered in the research. The views of co-ordinators, people with learning disabilities, volunteer befrienders and parents of younger children were analysed and discussed. The very positive nature of many befriending relationships is revealed. Difficulties in finding suitable activities that really increase community involvement are explored along with the sadness that is experienced when a befriending relationship comes to an end.

The results of this research were then used to inform the second book, Quality Measures for Befriending Services. Very clear quality targets are provided with recording sheets and examples of good practice. Both books are accessible, practical and easy to read. They would be invaluable to someone setting up a new scheme or evaluating an existing one. I think they would also be very useful as a resource for training new scheme co-ordinators or befrienders.

Readers of PMLD Link will no doubt be interested in how relevant these two books are for adults and children with profound and multiple learning disabilities. This group is not specifically mentioned so it is hard to tell how many of the befriendees/service users had multiple learning disabilities. A further project that researched the befriending needs of this group would be very welcome. Nethertheless, I would recommend these two books to readers of PMLD link because they are such a rich source of ideas for good practice.

Review by
Helen Bradley—Consultant Clinical Psychologist/Tutor
School of Education Birmingham University.

INTERCONNECTIONS ELECTRONIC BULLETIN ABOUT CHILDREN WITH DISABILITIES / SEN

November 2005

CONTENTS –

About this Electronic Bulletin

It comes from Peter Limbrick, in Interconnections. Peter is an independent consultant to statutory services in the field of babies and children with disabilities / SEN.

The Electronic Bulletin goes free to over 3,900 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.

If you would like a copy of Interconnections Electronic Bulletin

Peter Limbrick
Interconnections
9 Pitt Avenue
Worcester WR4 0PL
Tel/fax: 01905 23255
E-mail: interconnections.services@virgin.net

Report Back ....

***Parents as trainers*... read on!**

by Ann Fergusson, *PMLD Link* Editorial Team.

I recently attended one of several regional events to share the outcomes of research funded by The Foundation for People with Learning Disabilities (FPLD). The ***'Making Us Count'*** Seminar in London, ***Identifying and improving the mental health support for young people with learning disabilities**,* was a really inspiring day. The whole event not only centred on cutting edge research within the learning disability field, but it involved the very people at the heart of it all.

Some of the young people (with learning disabilities) involved in the projects shared their experiences with us, about their learning to understand and deal with their emotions. The presentation that really hit home for me though, was one involving parents of youngsters with profound and multiple learning disabilities (PMLD).It is rare to find research centred around this group of individuals, let alone with such forward-thinking principles.

The Well-Being project: identifying and meeting the needs of young people with profound and multiple learning disabilities and their carers is a piece of research led by Maureen Phillip of White Top Research Unit, University of Dundee. Its initial focus was on how carers identify and respond to the emotional and mental well-being of their son or daughter with PMLD. One of the outcomes of this research was the development of training workshops on the emotional and mental well-being of this group of youngsters, facilitated by Loretto Lambe of *PAMIS*. This development was the exciting bit - these training workshops were designed and delivered by parents of young people with PMLD!

The training they had developed was designed to inform parents, families, carers and front line staff and explored issues such as change and transitions, health issues, loss and bereavement and supportive therapies. Together the group had developed a very accessible workshop structure that was used for each theme. This included guided tasks, case studies (of their sons and daughters), buzz groups and discussion.

At the seminar, we heard from the parents themselves about how they developed the training materials by focusing on their area of expertise – their sons and daughters. By using their knowledge and experience, we were given some thought-provoking insights of why and how *their* youngsters expressed emotions or general well-being. These materials will soon be available from the FPLD website…watch this space!

A key comment from their presentation offered a valuable reminder that really resonates with me, when thinking about the quality of my younger brother's life and in my professional role within the field.

'Stand in the shoes of the person with PMLD before you make decisions on their behalf'.

Albeit with the best intentions (and with resources etc, etc, etc permitting), how well do we really do this?

Contacts:
Foundation for People with Learning Disabilities ; www.learningdisabilities.org.uk

PAMIS works with family members caring for a relative with PMLD; it aims to support families by ensuring they have informed collaboration with service agencies. www.dundee.ac.uk/pamis

NEWS, PUBLICATIONS AND RESOURCES


Changing Places Campaign

Accessible Loos For All

PAMIS has joined forces with MENCAP and a number of other organizations to form the **Changing Places Consortium.**

The aim is to take the ***PAMIS*** campaign forward to a wider audience throughout the UK.

The Changing Places Consortium will:

- Develop a web site – a one stop shop for advice and information
- Raise awareness of the need for fully accessible ‘away from home’ loos
- Produce publicity materials – fact sheets, leaflets and posters
- Distribute the ***PAMIS*** ‘Time for a Change’ video/cd

We will convince local authorities, planners and service providers of the need to provide Changing Place Loos.

'A voice of their own' - Advocacy Conference
3 March 2006, Birmingham

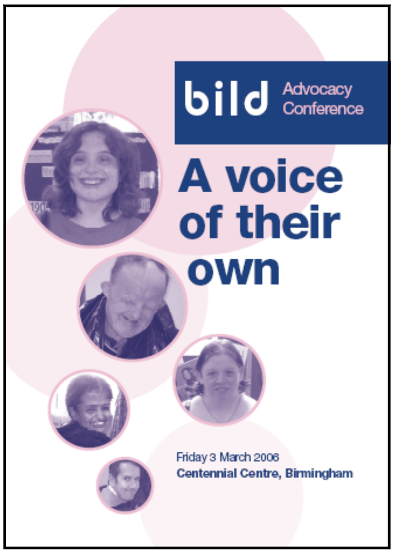


bild Advocacy Conference

A voice of their own

Friday 3 March 2006
Centennial Centre, Birmingham

At the heart of Advocacy is a respect for the dignity of a person and a belief that voicing their respect can have a transforming effect. Advocacy is based on the belief that we are all citizens with the same rights, responsibilities and potential for growth. Advocates believe there is a need to challenge the exclusion and discrimination that can be experienced by people with a learning disability by enabling them to access their human and legal rights.

BILD is actively involved in supporting and promoting Advocacy throughout the UK. This conference through a selection of topical keynote speakers and participatory workshops, the power of advocacy will be explored and how to include all those with a learning disability who will gain the most from advocacy intervention will be identified.

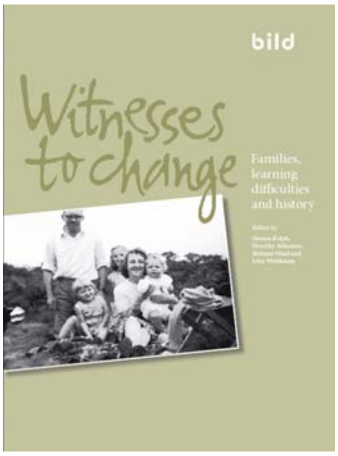
This conference will be beneficial to anyone interested in advocacy including those from health, social care, service providers, advocacy providers, self advocates and family carers.

Happy 70th birthday to talking books!

The RNIB Talking Book Service celebrates its 70th anniversary today. Since 7 November 1935 when the first Talking Books were issued, RNIB has sent out over 75 million audio books to over two million people with sight problems, making it one of the most popular and well-known services ever provided by a charity in the UK.

The RNIB Talking Book Service contains over 10,000 titles, making it the largest collection of unabridged audio books in the UK and one of the largest in the world. However, this still represents a tiny fraction of the number of books published every year in the UK - currently over 100,000.

Witnesses to change

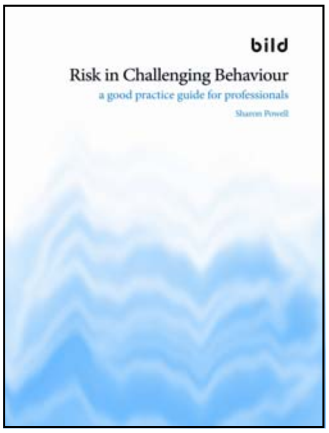


Author (s):	Sheena Rolph, Dorothy Atkinson, Melanie Nind, John Welshman
Publisher:	BILD
ISBN:	1904082750
Pub Date:	2005
Price:	£25.00

An important contribution to the history of learning disabilities, this new book focuses on changes in family life and learning disability in the twentieth century. The book includes the life stories of parents, as well as siblings, grandparents and other relatives from a wide variety of families from different social classes and ethnic groups.

Witnesses to Change highlights changes in policies, attitudes, services and lifestyles that have taken place over the last century and suggests future change and improvement in support of families.

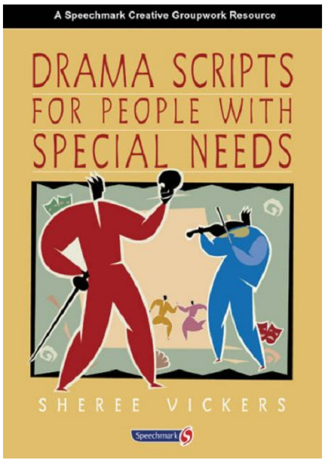
Risk in Challenging Behaviour



Author:	Sharon Powell
Publisher:	BILD
ISBN:	1904082 95 5
Pub Date:	2005
Price:	£12.00

This guide is designed to help with establishing a framework to support individuals with learning disabilities or autistic spectrum disorders whose behaviour challenges services and presents a risk to themselves or others. It sets out in clear and simple terms a structured and systematic approach to the identification, assessment and management of risks associated with challenging behaviours.

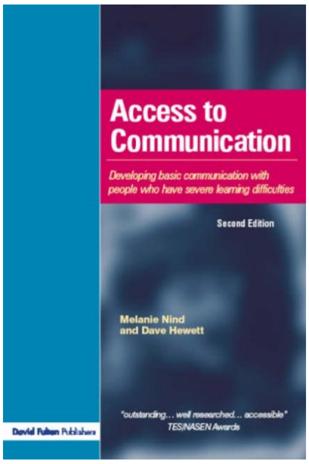
Drama Scripts for People with Special Needs



Author:	Sheree Vickers
Publisher:	Speechmark Publishing Limited
ISBN:	0863885292
Pub Date:	2005
Price:	£29.95

You may wish to use drama in a teaching or group situation but lack either the confidence to speak in character or the time to develop a role and/or workshop. This book solves both of these problems by providing the words to speak, an established well-worked lesson plan to use and an easy format to follow for multiple adaptations and future dramas. Intensely practical and hands-on, this is a book of scripts and drama-workshop breakdowns designed especially for people with special needs, including those with PMLD or Autistic Spectrum Disorders.

Access to Communication



Author (s):	Dave Hewitt & Melanie Nind
Publisher:	David Fulton Publishers Ltd
ISBN:	1843121840
Pub Date:	2005
Price:	£17.00

The award-winning creators of "Intensive Interaction" bring this groundbreaking book up-to-date with new material covering inclusion and emotional literacy. The book includes: a brand new section looking at Intensive Interactions implementation in pre-school settings, the particular benefits of Intensive Interaction for children who have ASD, a 'how to do it' chapter including ideas for assessment, and case studies to help practitioners get to grips with the realities of using Intensive Interaction. This book is meant for teachers and teaching assistants working in specialist schools and other care professionals and parents.

Short Courses and Conferences *2006*

CONTACT DETAILS

BILD

British Institute of Learning Disabilities
Campion House, Green Street,
Kidderminster, Worcestershire DY10 1JL
Tel. 01562 723025
E-mail: learning@bild.org.uk
website: www.bild.org.uk

Sunfield PDC

Clent Grove, Clent,
Nr. Stourbridge,
West Midlands DY9 9PB
Tel. 01562 883183
E-mail: Sunfield@sunfield.worcs.sch.uk

Concept Training

15 Beach Street,
Morecambe,
Lancastshire LA4 6BT
Tel. 01524 832 828
E-mail: info@concept-training.co.uk
Website: www.concept-training.co.uk/

EQUALS

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

Catalyst Education Resources Ltd

1A Potters Cross
Wootton, Bedfordshire MK43 9JG, U.K.
Tel. 01234 764 108
E-mail: FloCatalyst@aol.com
Web: www.cerl.net

Consent

Woodside Road
Abbots Langley
Herts WD5 0HT
Tel: 01923 670796
E-mail: consent.ESU@HPT.nhs.uk
Web: www.hertsparts.nhs.uk/consent

Some of next years short courses & conferences were not available at the time of print. Please visit their websites for updated information.

January

17th
Concept
Understanding the Multisensory concept
Oxford

18th
Concept
Understanding the Multisensory concept
Solihull, West Midlands

23rd
Sunfield PDC
Making Dance Special! (for children/young people with learning needs)
Led by: Dr. Melanie Peter – Senior Lecturer and Freelance Consultant
£97.50

24th
Sunfield PDC
PowerPoint for PMLD (Hands on Course)
Led by: Martyn Maltby – Deputy M.D & ICT Manager, Liberator Limited
£115.00 Ltd Nos

24th
Concept
Understanding the Multisensory concept
Wigan, Gt Manchester

26th
Sunfield PDC
Interesting Times – the power and passion of early development (0-5 years)
Led by: Maria Robinson, Independent Adviser in Early Years Development
£97.50

February

7th
Concept
Understanding the Multisensory concept
Peterborough, Cambs

15th
Consent
Supporting People With Learning Disabilities in Forming and maintaining Relationships
Abbots Langley
Phillip Jenner

16th
Concept
Understanding the Multisensory concept
Bradford

21st/22nd
Consent
Cultural Issues in Sexuality Work With People with Learning Disabilities
Ealing
Seema Malhotra

24th
BILD
Creative Communication Code
London

March

2nd
Concept
Understanding the Multisensory concept
Birmingham, Edgbaston

3rd
Sunfield PDC
Communicating through Movement – SDM – towards a broadening perspective *(cost includes a free copy of Communicating through Movement)*
Led by: Cyndi Hill, Sherborne Consultant
£45.00

3rd
Concept
Using Intensive Interaction
Peterborough, Cambs

7th
Sunfield PDC
A better way to share the news (about a difficult diagnosis)
Led by: Dr. Robina Shah, MBE – Psychologist, Research Fellow & Trainer
£97.50

8th
Concept
Understanding the Multisensory concept
Swansea

9th
Concept
Understanding the Multisensory concept
Taunton

7th/8th
Consent
Issues of sexual health for people with learning disabilities
Abbots Langley
Seema Malhotra/Jane Noonan

13th
BILD
Meeting the needs of people with profound learning disabilitiies
Warrington

16th
Concept
Understanding the Multisensory concept
Bristol

17th
Equals
Behaviour Management
London
Rob Long Chartered Educational Psychologist

21th
Concept
Understanding the Multisensory Concept
Edinburgh

22nd
Concept
Using Intensive Interaction
Crawley, West Sussex

23rd
BILD
Sexuality and personal relationships for people with learning disabilities
Warrington

30th
Consent
Care Plan/Guideline Writing for Sexuality Issues, Implementation and Reviewing
Abbots Langley
Daniel Wilson

April

4th
Concept
Understanding the Multisensory concept
York

4th
BILD
Health action planning
Warrington

5th
Concept
Using Intensive Interaction
London, Euston

LONGER COURSES (with accreditation)

June 2005 update

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

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

AdCert, BPhil, PGCert, PGDip, MEd.
An Interdisciplinary Approach to Learning Difficulties (Severe, Profound and Complex)
Distance education
This distance education programme has been developed for the range of staff who work with people with severe, profound and complex learning difficulties, for example teachers and lecturers, nurses, therapists, psychologists and support staff.

It is primarily about the learning and development of children and adults with severe, profound and complex learning difficulties, particularly in the areas of cognition and communication. Education, in its broadest sense, is seen as a key topic but other areas covered include health, therapy and social care. An important central theme is interdisciplinary / multi-agency collaboration and course participants will be expected to develop and reflect on their interdisciplinary work as part of course. All the course assignments are grounded in reflective and evidence-based practice and are driven by the individual professional development needs of participants.
For further details please contact: Dr Penny Lacey, phone: 0121 414 4878 or email: p.j.lacey@bham.ac.uk

Ad Cert, PG Cert.
An Interdisciplinary Approach to Learning Difficulties (Severe, Profound and Complex): Challenging Behaviour Route—*Distance Education*
This is not a separate programme but is a route through the programme called 'An Interdisciplinary Approach to Learning Difficulties (Severe, Profound and Complex)'. If you are primarily interested in learning difficulties and challenging behaviour you should study the following modules:

1. ***Learning Difficulties (Severe, Profound and Complex): Communication and Behaviour***
2. ***Interventions for Learning Difficulties (Severe, Profound and Complex)***
3. ***Special Studies in Special Education (project)***

Successful completion of these 3 modules will lead to Ad Cert or PGCert. If you wish to continue to BPhil, PGDip or MEd, you will study the second year modules from the main programme.
For further details please contact: Dr Penny Lacey, phone: 0121 414 4878 or email: p.j.lacey@bham.ac.uk

PGCert, AdCert.
Early Years: Sensory and Multiple Needs—This programme begins in January
Distance education.
This programme enables professionals to work more effectively with young children with sensory and multiple needs. Participants may be teachers, who may already hold a specialist qualification in visual impairment, deafness or multisensory impairment; specialist speech and language therapists; health visitors; social workers; carers or others working with young children with sensory and additional needs.
For further details please contact: Dr Liz Hodges on 0121 414 4873 or email: E.M.Hodges@bham.ac.uk

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

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

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

Students working on BPhil or Postgraduate Diploma programmes with some additional activities can, on successful completion, be recognised as meeting the requirements of the DfES for the mandatory qualification for teachers of children with multisensory impairments.

For further details please contact: Dr Liz Hodges on 0121-414 4873 or email: e.m.hodges@bham.ac.uk

MSc and Graduate Diploma in Learning Disability Studies

This course *is now Distance Learning only*

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

- I***s designed for experienced professionals involved in the care of adults and children with a learning disability.***
- ***Is a distance course, involving the use of specially-prepared texts, annual weekend schools, and local tutorial groups.***
- ***Assesses ability through small practical assignments and a dissertation of 15,000 words based on original research.***
- ***Can be completed in one-year (full-time) or between two and five years (part-time).***
- ***Leads to a Masters of Science degree after the completion of all assignments and the dissertation, or a Postgraduate Diploma for the completion of the assignments alone.***

For further details please contact: Dr Stuart Cumella, Division of Neuroscience on 0121 414 4507 or email: S.Cumella@bham.ac.uk

Postgraduate taught MSc 24-36 months months
Profound Learning Disability and Multi-Sensory Impairment MSc for entry in 2005 - *Distance Learning*

The course is aimed at students who personally and professionally come into contact with individuals with complex learning needs and sensory impairments, or who have a desire to gain the specialized knowledge related to this area of interest.

- ***To provide a unique opportunity for a wide range of people to acquire knowledge and skills to empower them to enable individuals with very complex needs to reach their full potential.***
- ***To provide an increased knowledge and understanding of children and adults who have complex learning needs and sensory impairments.***
- ***To enable those directly concerned with this group to advocate for the rights of the individuals concerned and work towards improving their quality of life and community presence.***
- ***To enable this to happen by providing current information relating to cognitive, emotional, physical, sensory and social needs.***

For further details please contact: Email pg-education@manchester.ac.uk or telephone 0161 275 3337

Postgraduate taught PG Diploma
Profound Learning Disability and Multi-Sensory Impairment PG Diploma for entry in 2005

24 months Distance Learning

The course is aimed at students who personally and professionally come into contact with individuals with complex learning needs and sensory impairments, or who have a desire to gain the specialized knowledge related to this area of interest.

- ***To provide a unique opportunity for a wide range of people to acquire knowledge and skills to empower them to enable individuals with very complex needs to reach their full potential.***
- ***To provide an increased knowledge and understanding of children and adults who have complex learning needs and sensory impairments.***
- ***To enable those directly concerned with this group to advocate for the rights of the individuals concerned and work towards improving their quality of life and community presence.***
- ***To enable this to happen by providing current information relating to cognitive, emotional, physical, sensory and social needs.***

For further details please contact: Email pg-education@manchester.ac.uk or telephone 0161 275 3337

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