

PMILD**LINK**

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

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*PMLD LINK relies on contributions from practitioners, parents,
carers and everyone interested in this field*

EDITORIAL

The topic for this issue was the creative arts and, in particular, the problems and solutions to accessing these activities. Articles range from management issues involved in moving and handling pupils, to a workshop on 'The Tempest' at the Globe theatre, and how pupils with physical disability participated in this activity. As well as articles on the topic, we have another contribution from a parent, and articles on subjects as varied as Flo's 'naughty rude curriculum' and information on bowel and bladder control.

Thank you to all writers who have given their precious time, and sometimes shared some very personal experiences with us.

Don't overlook the box at the end of the article "The sum of the Parts" - it is an invitation to all interested readers to the Mencap/PMLD-Link Seminar in London on 14th May. As readers who look at the *Report Back* section will know, Mencap holds regular seminars on issues of importance to people with PMLD and their carers and practitioners. Participation in these is by invitation, and this is the first time that PMLD-Link has been involved, and the opportunity offered to all readers to attend - with the proviso that places are limited and it must be on a first come first served basis. Attendance at the seminar is free, and refreshments are provided.

Future Focus

The next issue will focus on all the voluntary and independent organisations which carry out research or provide services of different kinds for people with PMLD and their families and the professionals who work with them. We are hoping to have information from many organisations, large and small, national and local to provide an information base which will help readers to find the services or information they need.

If you know of an organisation either nationally, or in your area which you think should be included, please let me know by telephone or e-mail (see bottom of page) as soon as possible so that we can get contributions in in good time for the next issue.

We would also like to know if there are any specific themes which you would like to be addressed in a future issue. Planning for next year's topics is done at our Editorial Group meetings, the next one is in October, so please let me know before then.

Business Matters

Most subscriptions have been renewed now, but if you intended to renew but have forgotten to do this, you will find a subscription form on the back page. If you have already renewed, please ignore it!

Articles on any topic for inclusion in the next issue should reach me by the end of June. Send them by post or e-mail (Rich Text Format please) to

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

"Daring to Dream"

My name is Jaynie - I am married and we have two fabulous sons, Euan 6 and Ross 4. I would like to tell you a bit about 'Partners in Policymaking' and what a huge impact it has had on changing my families life.

For those of you who have not heard of it 'Partners in Policymaking' is a course that runs over eight months at residential weekends. The idea for the course first came from America, where they realised before us - surprise, surprise - that parents of children with disabilities, and people with disabilities, should play a major part in how services are designed and delivered. and how we live our lives.

I was the person on the first day that stood up and said that I was fed up with every one banging on about inclusion - it couldn't work for Ross. I had tried not to think about Ross, not going to school with his big brother Euan - it was just to painful. I had all those feelings of keeping him safe, protecting him - I didn't realise it actually meant excluding him.

I can tell you I was well and truly put in my place.

I phoned my husband that first night and told him I didn't want to be here. I had always thought I had a good attitude towards people with disabilities, but here I was in a room with 13 self advocates, and suddenly realised my attitude was not that good.

I just didn't want to be part of that world.

I now know this was because I was brought up in an exclusive society where the boy down the road, wasn't allowed to play with us, and went to school in a blue mini bus.

You will be relieved to hear I don't think or feel this way now. I very quickly didn't see disabilities, but the people, and they taught me so much about how to do it right for Ross, for which I am eternally grateful.

The very word 'special' when used around people with disabilities gives us all comfort that best practice is in place. And that somehow some people are just so special that they need special units, special schools, special day centres.

I now know from the people with disabilities on the partner's course that to them 'special' means devalued, segregated, ignored, low expectations, no friends, no money, no prospects, no life, and even sometimes abuse.

Suddenly I personally felt responsible for this as I was part of a society that condones this, and I am just not prepared to let this continue to happen.

As the months went on even I began to grasp the concept that our two sons didn't need to travel different paths from each other, just because one has labels and the other doesn't. Ross doesn't need to be bussed to a different area, he can know and play with the other children in our street, and one day he may even be invited to a birthday party.

Before the partners course I knew the services we were offered were not what we wanted, but couldn't imagine better. But as you all know, if we say no too many times you don't get anything at all. So you accept what's not ideal or you lose your place in the queue.

At the beginning of the year I was doing some freelance work around Scotland with SHS Trust speaking to commissioners of advocacy, trying to make sure some of the most vulnerable people in our society have a voice. And what struck me again and again and again is that a lot of people actually don't need advocates, they only need friends. They needed to go to their local schools, be known and valued in their communities, and have friends that can speak up for them, and support them just the way our friends do for us. People's ordinary needs are every bit if not more important than their special ones.

Believing in inclusion is not always a comfortable place to be. I am often looked at as though I have landed from Mars, but I'm getting used to this and it gets easier all the time. I just keep remembering how amazing Ross is, and the wonderful gifts he has brought to our family.

One of the important things I took from the course was the 'authority of witness', and I know some of you know this already, but I think it's important that the professionals understand where families are coming from

I want all parents to know this, and remember this any time you feel under pressure, or have doubts about your strengths.

We have the authority - we know the child better than any one, we have more experience.

We care more than any one else, and we have invested more in them.

We have authority of witness - we're living it, every one else is only watching.

Every one expects us to advocate for our child - so let's do it.

We have the legal authority - so let's use it, and use it wisely.

And I think this the most important:

We think our children are wonderful and
love them more than any one else - so
let's tell every one how wonderful they are.

But the single most powerful thing I learnt on Partners was that it is okay to dream for Ross. I felt before that I couldn't do this for Ross as we are conditioned to believe that the system has all the answers.

Part of our dream has already come true, Ross is fully included in his local nursery, the same one Euan attended. There were teething problems, but the staff worked hard to overcome these, and now there is the most wonderful atmosphere that words cannot do justice to.

Ross is a big hit and with the ladies and has not one, but two girlfriends.

Children do not have an issue with difference we do.

I would like to share some of my dreams for the future with you now.

When I dare to dream, I have very clear picture of how I want the future to look for our family, and it no longer has anything to do with Ross meeting criteria, or making the grade. No other child has to pass a test to go to their local primary school, why should ours? Ross doesn't need to get better to go to mainstream - mainstream has to get better for Ross

to go there. I think it is very cowardly to put the onus on children to fit into the existing system when we know that if we create truly inclusive schools that they are better places for all children to be.

I think that if schools can't welcome kids with disabilities, they are not healthy places for any child to be.

When I dare to dream, I dream that the expertise that is currently only available in special schools, be available in all schools, so that we can all have real choices, we all have so much to share and learn for each other.

When I dare to dream, I dream that no more professionals will say that they are only considering Ross, and that he might be happiest at a special school.

Will they also be saying in 15 years that he would be happiest in a day centre?

And that it's okay if no one knows him in his community?

Will they also be saying that he is happy because people can only think of him as disabled, because no one knows anything else about him?

When I dare to dream, I dream of a society that values peoples differences, and one that has the humility and grace to realise that it does not always do things in people's best interests, but it is our own shortcomings and lack of imagination or commitment that is keeping people segregated.

When I dare to dream, I dream that both of our sons will be appreciated for what they can do not what they can't, I want them both to grow up in a society that's fair and just, and I want them both to be valued for their gifts.

When I dare to dream, I dream that no other parent will get the reaction I did when I expressed our wish that Ross be fully included in his local school. I dream that children with disabilities will be truly welcomed. And no parent will ever be made to feel as uncomfortable as I did.

We now have a presumption of inclusion from the Scottish Executive, so I am presuming inclusion:

I am not presuming a split placement;

I am not presuming a unit attached to a school;

I am not presuming a school that is not our local one;

I am simply presuming inclusion.

When I dare to dream, I dream of family support - that we start to think outside the boxes and ring fenced money; I often used to say that it was Euan that needed someone special, not Ross. Families know best what families need.

When I dare to dream, I dream that Euan and Ross will have school photographs taken in the same purple sweatshirts, and the school that Euan thinks is "the best school on the planet" is the one that welcomes Ross.

I want to tell you about a conversation I had with Euan when he was about five and a half - it went something like this:

Euan : " I can't wait for Ross to come to my school".

I then asked why

Euan with an extremely condescending look on his face, the kind that only a five-year-old boy can have "Because he is my brother and I love him, and brothers should be able to see each other during the day".

Me "Why else"

Euan "everyone elses brothers and sisters go to school with them, why shouldn't Ross?"

I explained to him that some people thought that Ross shouldn't go to school with him because he has autism.

And Euan said, "Well that's just stupid".

To me that says it all.

I believe that dreams create vision
Vision creates ambition
And ambition creates reality

Good luck in following your dreams!!

**A Parent
c/o PAMIS
Dundee**

Training and Support for Staff in the Moving and Handling of Dependent Pupils

St. Luke's School is a day special school for 80 pupils aged between 3 and 16 years with severe to profound and multiple learning difficulties. It is part of the special education provision maintained by North Lincolnshire Council which is a relatively small unitary authority created in 1996.

About 25% of the pupils have severe physical disabilities which mean that they are almost all totally dependent on others for having their major personal self-care needs met (e.g. personal hygiene, dressing and undressing); they require support for systematic mobility and physiotherapy programmes (including hydrotherapy); and they participate in a range of curriculum activities which demand actual bodily support for access (e.g. cradling by adults for movement activities) or being sat or stood in a specialist furniture to engage in activities.

Work with these particular pupils can be physically demanding on the staff. Staff have to engage in a range of activities which could pose a risk of injury to their bodies. For instance, helping teenagers to propel themselves in a gait trainer along a winding, narrow corridor for 100 metres as part of their mobility programme is tiring; simple physiotherapy activities require staff to make a range of movements in the space of a brief period (bend, stretch, kneel, squat, sit, twist, turn, rise); and attending to pupils' personal hygiene needs involves a series of transfers from chair or floor to wheelchair to changing bench as well as the physical effort involved in undressing and dressing. Work with small children is no easier: it does not help that an adult has to bend down to talk to them or sit on low chairs at low tables for activities at their level, for instance. Also, the cramped accommodation in a poorly designed building (particularly in the hygiene areas) does little to make tasks physically easier for staff.

Over the years, the senior management team of the school and its specialist advisers, especially the physiotherapist and occupational therapist, became concerned about the cumulative effect of activities on the musculo-skeletal systems of the staff. Also, an increase in the number of days lost to staff absences with a 'bad back' or other strains was becoming a concern. In a real sense, we were our own worst enemies because we put the developmental needs of the pupils above all else. Instead, we should have been considering the rights and needs of staff just as much as those of the pupils. We can see this with hindsight, but at the time we were more acutely aware of the need of good postural care for the pupils and the value of the increasingly sophisticated range of seating and other specialist furniture to support this.

The introduction of the MOVE curriculum in the early 1990s and the use of associated equipment produced by Rifton (especially gait trainers) also enhanced opportunities for these pupils greatly, but increased the physical demands on staff. The provision of a hydrotherapy pool by a local charity in the mid 1990s, greatly improved the range of physiotherapy activities for the pupils but further stretched staff physical capabilities. Finally, much of the new equipment that became available for physical development activities was initially designed without much thought about the physical demands that it made on staff; and some equipment required pupils to be supported in a seated or standing posture whilst numerous adjustments were made to fastenings, etc.

Of course, we did take a number of steps to improve matters. We drew up a policy on moving and handling. Procedures for getting pupils in and out of the hydrotherapy pool using a poolside hoist were carefully set out. Steps were taken to improve the accommodation in the hygiene areas - sometimes it was sufficient to give staff regular

reminders about reducing clutter. Mobile stools on castors were purchased so that staff could move around and remain in a seated position when working with small children at tables and when assisting all sizes of pupils in mobility programmes. On the advice of the therapists, we purchased two mobile hoists, trained staff in their use and insisted on these being used when moving and handling any pupils where we considered that there were possible risks to pupils themselves or to the staff.

Finally, we encouraged staff to plan more carefully the various routines during each day so that the number of events of moving and handling could be reduced. This helped matters greatly, but concerns remained. Moreover, it was reported to us that more stringent European Union regulations on moving and handling would be introduced at the turn of the millennium.

What we had to do was reasonably clear to us:

- We had to audit the range of moving and handling activities that were regularly occurring;
- We had to assess more systematically the risks of physical harm to staff and pupils;
- We had to decide whether unnecessary activities were occurring;
- We had to decide what mechanical assistance could be made available to minimise unavoidable risks;
- We had to raise staff awareness about the risks;
- We had to arrange suitable training for staff;
- We had to ensure that a more comprehensive policy on moving and handling was developed;
- We had to meet the therapeutic needs of the pupils as defined by the physiotherapist, e.g. teaching pupils to do transfers, when this was in their capability, rather than automatically using a hoist to do transfers.

Our first stumbling block was that the council's own guidance on risk assessment had more to say about moving inanimate items than moving and handling children and young persons with floppy or flailing limbs. Indeed, the very first day of training which we arranged for staff was quite limited in its usefulness because all they were shown were the biomechanics of lifting and the best ways of moving boxes and equipment. We determined that all future training and risk assessment had to take place with real pupils and in typical school settings.

Our next problem was that the people with the specialist knowledge - the physiotherapist and the occupational therapist - were not trained to do risk assessments themselves and were not insured to act as instructors in moving and handling. The local NHS Trust's back care adviser was appropriately qualified but was authorised only to train health service employees. However, the therapists were able to give us information about a team of people - all physiotherapists working for a neighbouring health service trust - who were qualified to conduct risk assessments and deliver training.

This group was commissioned to do a one-day preliminary visit to the school to survey our working practices and make suggestions about our needs. Unsurprisingly, they identified a number of unsafe practices, even in classrooms where the staff were very experienced and had a high degree of skill and expertise. They recommended a package of training - a day's 'emergency' training for all of the staff on basic principles and training for selected staff so that they could function as the school's own risk assessors and trainers.

Two teachers were identified to train as risk assessors - a member of the senior management team and the PE subject leader - and they joined other trainees for a five-day course at a clinic some 20 miles away in November 1999. Needless to say, the net cost to the school of this training was several thousands of pounds. However, the two teachers returned to school buzzing with new ideas and fresh insights and armed with appropriate formats for risk assessments.

The release of the two teachers from their class responsibilities to do risk assessment and training in other classes was inevitably an expensive business for the school too. Doing risk assessments thoroughly and communicating the results to class teams is time-consuming if it is going to be done well. Also, it has to be repeated regularly. The process tested the knowledge of risk assessors to the full. They also had to be tough-minded and, where necessary, outlaw practices that they deemed unsafe. On their recommendations two more mobile hoists were purchased - both of these can be folded neatly and taken on to the school minibus for use during off-site educational visits to places where there are no suitable facilities. Finally, the risk assessors and the Deputy Head, in consultation with the rest of the school staff, reviewed and revised the school policy on moving and handling.

For a while, we were reasonably satisfied that our procedures and risk assessment formats were of good quality. However, the risk assessors were somewhat concerned about several issues. Their first concern was that sufficient allowance should be made in school budget planning for their own need for refresher training, required every two years, and for non-contact time to conduct regular reassessments of risk in relation to each individual pupil and to prepare regular refresher training for staff on a rolling programme. Their other concerns related to quality control. Even though they would have the opportunity of refresher training after two years, there were no interim checks on the quality of risk assessments and training they provided. They only had recourse to advice from the people who had trained them. Moreover, the training for the risk assessors would be much improved if it took place in situ using equipment and facilities in the school. Also, where was the insurance cover if they unknowingly advised staff wrongly and an accident happened to staff or pupil?

Matters were complicated further when the DfEE approved in 1999 Local Education Authority proposals to reorganise its special schools. The LEA has developed a plan based on the re-organisation of St. Luke's School and its all-age school for pupils with moderate learning difficulties into generic primary and secondary special schools, each catering for a wider range of needs. The new schools are due to open in September 2002 and by September 2004 will be located in new 'state-of-the-art' buildings with vastly improved accommodation.

This change in provision means that the pupils with physical disabilities in St. Luke's School will be spread across the two new schools and that a wider programme of training is required both to ensure that there are risk assessors in both schools and that all staff receive appropriate training. A number of key requirements have already been met, such as the appointment of senior management teams and teachers for the new schools, although support staff have yet to be appointed.

The LEA has given an appropriate emphasis on training, development and support for the new schools. Funding will enable the training of identified would-be risk assessors in both schools and this will take place shortly. The Special Educational Needs adviser for the LEA has given effective support for developing the necessary policies and procedures for moving and handling in both schools by commissioning and funding a training company to provide advice and initial accredited training for the risk assessors. The new training company has a package that addresses the concerns about quality control and the corporate Health and Safety section of the council has endorsed the LEA's approach to this matter. The eventual outcome should be an agreed LEA policy on moving and handling which clarifies the responsibilities of all schools and the support available to them.

Inevitably, budgetary and planning problems remain for both schools. Although the new special schools will have much improved accommodation and in-built mechanical hoists, the maintenance of these will be costly and will have to be met from the schools' own budget. The same applies to all other training costs and the supply cover for non-contact time required by risk assessors. These costs have to be recognised as recurrent costs and met by the governing bodies. Also, a rolling programme of training must be identified and built into each school's improvement plan, in the face of other competing demands for training in relation to the curriculum and other matters of pupil welfare. It is highly doubtful that the DfEE and LEA designers of special school funding formulae ever entertained the possibility of such costs when allocating funds. Certainly, our council has no centrally held budget to support schools in these matters.

Needless to say, the problems that we have encountered at St. Luke's School, are precisely the problems faced by others up and down the country in special schools and increasingly in mainstream schools which provide inclusive education for pupils with physical disabilities. Also, like us, other schools now take steps to assess risks in relation to moving and handling of pupils and give staff appropriate training and aids in order to ensure that risks are kept within acceptable bounds, as a matter of course. However, our casual conversations with staff from other schools suggest that in some schools, practices are not as safe and well-established as they should be. We hope that this brief account of how we have fared in trying to safeguard staff as well as pupils is helpful to staff from those schools. We do not pretend that we have developed a no risk system, indeed it is questionable whether risks can be eliminated altogether, but we do feel that our school community has benefitted.

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

If you wish to have further details about procedures and equipment in place at St. Luke's School, please do not hesitate to contact Alison Harland at the school (Tel: 01724 844560).

'Raising a Storm' **The Tempest on stage at Shakespeare's Globe Theatre**

This article describes a series of workshops now taking place at Shakespeare's Globe Theatre (February-March 2002), with a group of pupils with profound and multiple learning disabilities from Charlton School in Greenwich.

All of the pupils in this group have very high support needs, but managing the handling and lifting procedures has been remarkably straightforward, thanks to the highly organised staff of Charlton School and the commitment of the staff of the Globe Theatre. The school buses are allowed to park right outside the stage door, where they are received by the staff of the Globe Theatre. A hoist is brought along from school to transfer one pupil, who has a dual sensory impairment, from her wheelchair onto the stage floor so that she can feel the resonance of the activities through the wooden stage. The Globe Theatre has a very large lift from the ground floor to the stage, and so the entire group is taken up together.

The three aims for the workshops are as follows:

1. For participants to experience the story line, the atmosphere and the language of Shakespeare's 'The Tempest' in performance on stage at Shakespeare's Globe Theatre.
2. For participants to develop language and communication skills within the framework of the poetry workshops.
3. For participants who are switch users to have the opportunity to initiate each activity.

Each of the six activities contain extracts of original text which is performed in call and response (one or more persons calling out the words, and the others then repeating those words or responding by any movement or sound). The final line of each activity, as indicated in italics, are called out by everyone together. Participants with sensory impairments may also use a drum or tambour, and the resonance of the wooden stage. In the classroom sessions, a resonance board can be used. Participants also use VOCAs (Voice Output Communication Aids). Each of the workshop activities can be initiated by a switch user saying the first line, as indicated in italics. Each first line is also time-independent and can be used repeatedly throughout each activity.

THE TEMPEST

Caliban to Prospero

Storyline: Caliban, a monster, is the slave of Prospero who lives on the enchanted island with his daughter Miranda. Caliban and Prospero hate each other, and nearly all of their exchanges are curses and insults. This is Caliban, enraged, cursing both Prospero and Miranda.

Aaarrggghh!!
You taught me language
And my profit on't
Is I know how to curse.
A south-west blow on ye

And blister you all o'er!
All the charms of Sycorax
Toads, beetles, bats
Light on you!
The red plague rid you
For learning me your language!
Aaarrggghhh!!

Activity: this activity is initiated by an angry roar recorded onto the switches. The first three lines of this call and response sequence are spoken at average volume, and the rest is shouted, roared, or bellowed as loudly as possible, finishing with everyone giving a very loud roar of rage.

Prospero to Caliban

Storyline: Prospero answers Caliban's cursing with threats and curses of his own:

(Nasty threatening roar, starting softly and getting very loud)

For this, be sure,
To-night thou shalt have cramps
Thou shalt be pinch'd
As thick as honeycomb
I'll rack thee with old cramps
Fill all thy bones with aches
Make thee roar

(Nasty threatening roar, starting softly and getting very loud)

Activity: These words are spoken in a soft but threatening manner - started and concluded by a roar that begins quietly and builds up to a very loud volume (this also distinguishes it from the roar on activity 1)

Ariel to Ferdinand

Storyline: Ariel is a spirit controlled by Prospero who has created by magic a tempest that has caused a shipwreck. Ferdinand, who thinks he may be the only survivor, hears the magical song of Ariel, who seems to be telling him that his father has been drowned.

Sound of a bell

Full fathom five thy father lies;
Of his bones are coral made;
Those are pearls that were his eyes:
Nothing of him that doth fade,
But doth suffer a sea-change
Into something rich and strange
Sea-nymphs hourly ring his bell

Sound of a bell

Hark!

Sound of a bell

Now I hear them

Sound of a bell

Activity: In contrast to the previous activity, this is calm and quiet, beginning and ending with the chiming of hand-held bells. The activity begins with the pre-recorded sound of a bell from a switch.

Caliban to Trinculo and Stephano

Storyline: Trinculo and Stephano and Caliban all get drunk together, and Caliban sings that he will no longer serve Prospero.

(Sound of a drunken hiccup!)
No more dams
I'll make for fish
Nor fetch in firing
At requiring
Nor scrape trencher,
Nor wash dish:
'Ban
'Ban
Cacaliban!

Activity: A loud and boisterous chant with drums and tambours, with the last three lines ('Ban, 'Ban, Cacaliban' repeated twice or more), initiated by a loud drunken 'hic!!' recorded on all switches. Participants can also sway from side to side.

Tempest Language

Storyline: The vocabulary and imagery of the sea occurs throughout 'The Tempest', a play that contains an unusual amount of compound nouns and adjectives invented by Shakespeare. This sequence of compound words is a selection of this distinctive language

Sound of an ocean-drum
Sea-sorrow
Wave-worn
Sea-change
Cloud-capp'd
Sea-storm
Thunder-stroke
Sea-swallow'd
Spell-stopp'd
The gong is sounded, fading to silence

Activity: This recital starts quietly, gradually gets louder, and then on the final line, everyone 'freezes' at the sound of the gong. The silence is held as long as possible. The activity is started by the sound of an ocean drum recorded on a switch.

Prospero

Storyline: The Tempest ends in peace for everyone. These are some of Prospero's famous concluding lines describing the play, the theatre, and human life itself, as a dream.

Sssshhh
Our revels now are ended
We are such stuff
As dreams are made on
And our little life
Is rounded with a sleep
Sssshhh

Activity: A quiet activity, beginning and ending with a 'Sssshhh' to end the workshop. A parachute is raised and lowered as the lines are spoken, and released on the final 'Sssshhh' to cover everyone.

The rationale for the first aim: for participants to experience the story line, the atmosphere and the language of Shakespeare's 'The Tempest' in performance on stage at Shakespeare's Globe Theatre.

Human learning presupposes a specific social nature and a process by which children grow into the intellectual life of those around them' (Vygotsky, 1978, p88)

Life experiences and opportunities for people with the highest support needs are often very restricted, and so Vygotsky's observation presents us with an interesting challenge. If we do share a 'social nature', and the 'intellectual life' of a shared cultural heritage, how might we include people with multiple disabilities? These workshops are an exploration of this question. Shakespeare seemed an obvious starting point: his monumental and enduring influence on English language and culture has been described by Bernard Levin in one long and enthusiastic sentence:

'If you cannot understand my argument, and declare 'It's Greek to me', you are quoting Shakespeare; if you claim to be more sinned against than sinning, you are quoting Shakespeare; if you recall your salad days, you are quoting Shakespeare; if you act more in sorrow than in anger, if your wish is father to the thought, if your property has vanished into thin air, you are quoting Shakespeare; if you have ever refused to budge an inch or suffered from green-eyed jealousy, if you have played fast and loose, if you have been tongue-tied, a tower of strength, hoodwinked or in a pickle, if you have knitted your brows, made a virtue of necessity, insisted on fair play, slept not one wink, stood on ceremony, danced attendance (on your lord and master), laughed yourself into stitches, had short shrift, cold comfort or too much of a good thing, if you have seen better days or lived in a fool's paradise - why, be that as it may, the more fool you, for it is a foregone conclusion that you are (as good luck would have it) quoting Shakespeare; if you think it is early days and clear out bag and baggage, if you think it is high time and that is the long and short of it, if you believe that the game is up and that truth will out even it involves your own flesh and blood, if you lie low till the crack of doom because you suspect foul play, if you have your teeth set on edge (at one fell swoop) without rhyme or reason, then - to give the devil his due - if the truth were known (for surely you have a tongue in your head), you are quoting Shakespeare; even if you bid me good riddance and send me packing, if you wish I was dead as a doornail, if you think I am an eyesore, a laughing stock, the devil incarnate, a stony-hearted villain, bloody-minded or a blinking idiot, then - by Jove! O Lord! Tut, tut! for goodness sake! what the dickens! but me no buts - it is all one to me, for you are quoting Shakespeare (Levin, 1983, 167-168).

The rationale for the second aim: for participants to develop language and communication skills within the framework of the poetry workshops.

The main aim of these activities is for switch users to have opportunities to *initiate* each of the exchanges. The pre-recorded words or sounds are also time-independent, so that switch users may contribute throughout the exchanges. Other skills include:

Awareness: demonstrating any kind of awareness of the sights and sounds of the activities.

Anticipation: for example, demonstrating an anticipation of the loud donkey noises that end two of the activities.

Turn-taking: Participating, in any way, in the turn-taking call and response structure of the activities.

Showing self: the participant demonstrates a 'this is me' behaviour to gain someone else's attention by, for example, smiling, laughing, eye contact, and vocalizing.

Showing objects: this is a 'look at this', attention-sharing behaviour.

Giving objects: in contrast to the 'showing objects' behaviour.

Seeking physical proximity: moving, or turning, towards another person to indicate intention or desire to communicate.

Gaze alternation: Looking from an object to someone else - or vice versa - as a means of sharing attention.

Joint attention: Two or more people are intentionally looking at the same thing (or person) at the same time.

Declarative pointing: pointing to an object, while looking at the communication partner before during or after the point, to indicate 'look at that.'

The rationale for the third aim: for participants who are switch users to have the opportunity to initiate each activity.

Anecdotal evidence suggests that many AAC users may often be provided with switches to respond to questions, they do not always have the opportunities to *initiate an interaction*. Switch users may be provided with a pre-recorded message that is the final line of an exchange, or of a song or story. It seems a priority that, when an aim is encourage the use of a switch and its social functions, we should also provide opportunities for users to initiate and secondly to practice a new skill. Therefore the lines that that start each activity are context-setting, and then become time-independent, ie they can be repeated as often as possible throughout the activity.

Conclusion

Anyone who is interested in this version of 'The Tempest' but is out of reach of the Globe Theatre may be interested to know that the workshop script was practised in school for several weeks before visiting the Globe. Although we are very priveleged to have access to the theatre, the workshop itself can be done anywhere. The only essential requirements are communication aids and the enthusiasm of staff; the parachute, glittery cloth, chime bars, gong and drum are optional extras. Anyone who wants to discuss the workshop material in more detail is welcome to contact me.

Keith Park

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THE SUM OF THE PARTS

An inclusive dance and visual arts residency at Sunfield

During 1997-2000 an arts initiative SUNMOVES was developed at Sunfield School. This involved 2 artists in residence who were a dance artist (Peppy Hills), and a land artist, (Mike Fletcher), who led practical workshops which explored students' responses and provided access to the project for non-verbal students. The focus of the project was to develop the creative potential of the school grounds, working with students and staff as well as local schools and community groups. The initial phase of this project has been documented in various articles in *Special Children* (April 2001), *Animated-Summer 2000* (Foundation for Community Dance), including others.

It is against this backdrop that subsequent arts residencies and activity days have taken place. As one of the original artists involved in SUNMOVES, I was pleased to be able to continue my involvement with Sunfield when asked to co-devise a dance and visual art project for Autumn 2001. The other artist, Tess Hills, had also been involved in SUNMOVES, working with Sunfield and local High School students in a visual art initiative 'Outside In', that focussed on using stimuli from the land art outside, for indoor art pieces in 1999.

Our brief in Autumn 2001 was to develop dance and visual artwork with the students that could be shared as part of an end of term presentation to parents in December. Both Tess and I were familiar with the students and staff, and this gave us valuable insight during the planning stage. We were both very keen to make the project as inclusive as possible. During SUNMOVES the various opportunities for friends and families of students, and local community members to be involved working alongside each other in practical arts sessions, had provided exciting and unique experiences for all involved. We were also aware that for many students, appearing on stage as part of a live presentation to parents was neither a comfortable, nor appropriate experience. However, we did want these students to be involved, and valued within the project, so aimed to devise a project that enabled access at many points, and different levels of participation.

With a focus of access and high quality art experiences we decided to create an installation on stage. The visual artwork made by students acted as a backdrop and also defined the performance space.

Siblings Day

The project started with a day of visual art for brothers and sisters of students at Sunfield. Activities included:

Mark making - exploring pattern and repetition. Participants used charcoal, pastel and rubbers to create compositions. Music was played whilst people were drawing to encourage fluidity and spontaneity of movement and expression.

Relief panels - use of pattern and repetition. Participants used matchsticks, lolly sticks, buttons, wire etc to create intricate raised compositions that were stuck onto sheets of MDF.

Tape Art - using masking tape to mark out patterns (stencils) onto large pieces of cloth.

Many of the pieces of work created on Siblings Day were used as stimulus and basis for later workshops with students at the school.

Follow up Visual art workshops - Sunfield students.

Tess was given a base room to use where most of the visual arts workshops took place. This enabled her to set out materials and not have to constantly pack up and un-pack had she moved from classroom to classroom. Tess also worked within some SIECCA classrooms as many of these students find unfamiliar journeys stressful. Another example of ensuring the project was inclusive.

A number of classes were identified and visited Tess at her base for 3 consecutive weeks. Sessions were kept reasonably short (30-45 mins), so as many students could be involved as possible. The nature of the activities were 'dip in', hence it was not crucial to the art works that students were constantly engaged for a particular time span. Staff accompanied students and supported their involvement, often getting involved themselves. Many commented on their personal enjoyment of the activities and identified a desire to continue these activities in the classroom on a regular basis. Students were able to engage with the activities as they were different, accessible and enjoyable.

Activities included:

Print making - using material called 'Formy Foam'*. Tess took casts from the siblings' relief panels to create printing blocks. Students used these blocks and intricately cut vegetable blocks with water based inks to print onto large sheets of cloth and tissue paper.

Painting banners - students used paintbrushes, rollers, sponges etc to apply colour and pattern onto pre-prepared banners. Once dry, the masking tape (see tape art Siblings' Day), was removed and batiked wax (artist applied), was ironed off.

Painting panels - students used a variety of tools to apply colour and texture onto the relief panels created on sibling's day.

Dance Workshops -

Students and staff took part in practical dance workshops over a 6-week period. Days were divided as follows:

- Morning:* Class specific - general warm up, group dances and individual and duet work. A number of classes took part in these.
- Afternoon:* Performance group - students invited from different classes to develop a piece that would be presented to parents on stage.
- Twilight:* Community Dance Group - members from Clent (children and parents), and Sunfield students and care staff from one of the houses at the school. This group were also involved in a live sharing of work on stage.

Dance pieces were built up from students' spontaneous movement ideas that were then linked together.

The Performance and Sharing of work

In order to represent all those who had been involved in the project, the performance and sharing to parents took the following format:

Dance piece by Sunfield care staff, students and parents and children from Clent;

Dance piece by Sunfield staff and students;

Brief verbal explanation of project process by artists;

Slides projected onto back wall of stage showing Sunfield students (who had not been on stage), and siblings creating the visual artwork.

Reactions

Staff, (past and present), students and parents were staggered to see the impact that the artwork made.

The artwork was so powerful for several reasons:

- It was original work by the students, siblings and staff. It was clear the work had not been manipulated to 'look right'.
- The work was installed to a professional standard. As part of the project a specific number of days were allocated, in addition to the practical sessions run at Sunfield, for Tess to collate the artwork into a series of 11 foot banners that were suspended on and around the performance space.
- Use of colours - specific colours were selected for use throughout the project to ensure impact, (and to minimise stress for those who were particularly susceptible to visual stimuli).
- The dancers coped very well moving within the hangings, and the installation stayed intact throughout the performance!

The dance work was strong as:

- It was fun and it showed! Participants were actively engaged and were enjoying moving and dancing.
- The choreography had been based on students' movements.
- The piece had a clear form - beginning, middle and end.
- Each piece was different in content and tone.
- Dancers were dancing together within a group of Sunfield students, staff and children and parents from the local Community.

The combination of quality visual art and dance work was stunning. We were delighted at how well all elements, (visual art, dance, lighting, music), came together to create a quality piece of art. Many parents commented after the sharing how astounded they had been at the performance and sharing of work.

The success of the project - key elements:

Artists were involved in the conception of the project, hence the format could be devised around the artistic focus.

An outside eye (artists), brought fresh ideas, and specific expertise and skills. These have a legacy: techniques learnt by staff during sessions can be repeated in their own class time.

Access - the project was designed to provide varied access points for a range of participants.

Value - everyone's contribution was valued. People who were not seen on stage, (siblings, some Sunfield students) were represented via slides.

Quality - we had high expectations of all project participants, including ourselves. These expectations were based on past experience of working at Sunfield.

Partnerships - working in collaboration with staff at Sunfield enabled us to ensure that students were being stretched, whilst also enjoying activities. The staff's knowledge and support of the students was crucial.

The school's partnerships with artists continues to thrive. From our experience, such partnerships create exciting and engaging learning opportunities on many levels for ALL involved.

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* Formy Foam suppliers: NES Arnold (North West Educational Supplier), ESPO (Midlands Educational Supplier).

Joint Seminar organised by Mencap PIMD and PMLD-Link

On 14th May 2002

Mencap Meeting Room, Golden Lane London

***What Makes the Difference? Linking Parent and Professionals:
Meeting the Needs of People with
Profound and Multiple Learning Disabilities***

This Seminar is one of a series organised over the past three years by the Mencap National Officer for Profound and Multiple Disability

In the recent MENCAP Report - *Valuing People: Voices Unheard* many issues were raised on the quality of links between parents and professionals and the quality of service received by people with Profound and Multiple Learning Disabilities. This seminar is intended to provide a forum to extend discussion of these issues. Prof. Barry Carpenter OBE, will chair the Seminar and speakers will include parents and professionals.

Readers of PMLD-Link are invited to participate in this Seminar

For further information and application form please contact:
Beverley Dawkins, National Officer for PMLD,
at Mencap, 123 Golden Lane, London EC1.

telephone: 0207 454 0454
e-mail: beverley.dawkins@mencap.org.uk

A Naughty Rude Curriculum for All

I call you bad, my little child,
upon the title page,
because a manner rude and wild,
is common at your age.

Hilaire Belloc

Can you remember the childhood education you received at school? I do not mean the official education, but the rude, sniggering, hidden curriculum - not found in the classroom but on the back seat of the bus, behind the bike shed or in a close knit circle of friends. It was a closed curriculum, defiant against adults and matters 'proper'. I vividly remember rude poetry from 50 years ago.

Sam, Sam, the dirty man,
washed his face in a frying pan.
He combed his hair with a donkey's tail
and scratched his belly with a big toe nail

What's for dinner? What's for dinner?
Iris spew, Irish spew
Sloppy semolina, sloppy semolina,
No thank you, no thank you!

I still have an autograph book with naughty rhymes . . .

Eeny, Meeny Miney, mo
sit the baby on the po
when he's done,
wipe his bum,
tell his mummy what he's done!

Oh honey, you're a funny 'un,
with a face like a pickled onion,
a nose like a squashed tomato
and teeth like green peas!

The vocabulary on offer in these poems is not usually found in reading primers or spelling lists - words like poop, zits, farts, pee are not considered 'proper' - but are fascinating to all children. With inclusion, just consider that all children should access the hidden curriculum of childhood - including the very special children. See if you can offer a naughty curriculum so that everyone is included in the giggles. It's hard to get behind the bike shed in a wheelchair

Poetry offers a range of rudeness. Try some of the following books. They are not classics, but they are funny, with playground humour and a good rude laugh.

The poet Gez Walsh (1) says "some people do not agree with the subject matter which I use to encourage children to read and write, saying it is too crude. Personally, I would rather have a child try to spell the word 'fart' than not try to spell at all". Hear, hear! A good example of Walsh's work is:

"The Spot on my Bum"

**Good grief, this spot on my bum.
I've squeezed it so much
that my cheeks have gone numb!**

Other rude poems by Walsh include "The Return of the Spot", "Someone's Nicked my Knickers", and "The Man in the Skirt". These are published by King's England Press (see www.kingsengland.com for information) who also publish a range of rude poems by Andrew Collett, such as:

Other poems by Collett include "Bottling Burps for Grandma" and "Dad's Exploding Underpants". Andrew Collett and Gez Walsh also do performances in schools and can be contacted by telephone on 01484 663790.

"Always Eat your Bogies"

**Always eat your bogies,
don't wipe them on your clothes.
Just gulp them down in one,
as you pick them from your nose!**

Jonathan Long and Paul Korky (illustrator) have created a series of narrative epics with sensory potential and strong rhythmic humour, including:

The Duch That Had No Luck (Red Fox, 1999)
The Dog that Dug (Red Fox, 1993)

The Cat that Scratched (Red Fox 1997)
The Wonky Donkey (Red Fox 2000)

Try the pottypoets.com web site for potty poems.

Another potential area for a naughty curriculum is in science. Witness the on-going fascination of children with "Whooppee" cushions, for example.

Grossology is the latest science craze in America, devised by science teacher Sylvia Branzei. It presents a science of really gross things, linked directly to a child's life and how they view the world. Branzei (2) says " Now if I walked into a classroom and said 'raise your hands if you want to learn about the excretory system', no one would move. If I walked into a classroom and say 'raise your hand if you want to learn about spitting, burping, pooping, peeing and farting' all the kids raise their hands!"

Gross cookery forms part of grossology and you can find recipes for 'boogers on a stick', 'brain cell salad', 'strained eye balls', 'tongue toast' and more. Here is an example:

"Simple Pimples" Recipe

Ingredients: Ripe cherry tomatoes and soft cream cheese spread.
Preparation: Core the tomatoes. Drain excess tomato juice. Fill holes with cream cheese.
Give each 'pimple' a gentle squeeze - arrange 'tastefully' on a plate

Other grossology books by Branzie (3,4,5) include numerous activities and games. Related webs include:

wgh-graphics.com/barbie/gross.html	Loads of ideas and gross facts, such as your butt makes different fart sounds depending upon whether your anus is tight or relaxed!
www.yucky.kids.discovery.com	Billed as "The Yuckiest Site on the Internet" - find out about the human body, the word of works or cockroaches, belches, ear wax eye gunk spit, vomit - fascinating!

Finally, use modern technology to create scientific body sounds through "Listen hear!" sensory software from the Granada Learning Catalogue (www.granada-learning.com). The program provides over 90 recorded sounds that can be manipulated and changed - put on a loop, for example. It includes burps and cries and you can experiment to create your own rude sounds using a microphone and the built-in sound recorder in Windows.

Good burping and good luck!

Flo Longhorn
Catalyst Education Resources Ltd.

References:

- (1) Gez Walsh. 1997. *The Return of the Spot*. King's England Press, p. 80
- (2) Anil Ananthaswamy in "Opinion Interview" *New Scientist* 22-29 December 2001, pp. 73-74
- (3) Sylvia Branzei, Jack Keely (illustrator). *Grossology: The Science of Really Gross Things* (Grossology Series). Planet Dexter
- (4) Sylvia Branzei, Jack Keely (illustrator). 1997. *Virtual Grossology: See It! Touch It! Hear It! Smell It! Taste It!* (Grossology Series). Planet Dexter
- (5) Sylvia Branzei. *Grossology*. Puffin Books (expected 28 February 2002)

Also look up the rude and naughty page on the Resources and Links page of our Web site (www.cerl.net/links.htm) and send us your own ideas for others to share. All will be published!

'Hello You'

Circles Network CREDO Project Video

A 45 minute video which focuses on the lives of young people with profound and complex impairments. The film covers the following areas:

Circles of Support
Person Centred Planning
Communication
Direct Payments
Growing up
Inclusion and Friendship
Personal Assistants
Supported Employment
Death of a child

Available from:
Circles Network, Potford's Dam Farm, Coventry Road, Cawston, Rugby CV23 9JP

Tel: 01788 521078 e-mail: mandy@circles.demon.co.uk

Raising Bladder and Bowel Awareness with Children

Extent of problems

Incontinence problems are common in children, with bedwetting affecting half a million children between five and sixteen years out of a population of 8.4 million (ERIC 2001). Bedwetting is known to have often devastating effects on a child's self-confidence and self-esteem. Day-time wetting is not as common a problem but still affects 1 in 8 eleven year olds and 1 in 33 sixteen year olds. Childhood soiling is again common - for example about 1 in 100 children are affected of age 10-12 and older (ERIC 2001). For children with physical disabilities such as cerebral palsy, some either have a delay in gaining continence or are never able to achieve full control.

Help is available

For those children who have these difficulties it is important that they are assessed and treated to maximise the chance of continence, by a health care professional who is adequately trained in this speciality - contact your local Continence Specialist team for further advice via the Continence Foundation Helpline mentioned at the end of this article. ERIC, or the Enuresis Resource and Information Centre also have a telephone helpline for children, parents and professionals on 0117 960 3060 open Monday to Friday 10-4pm.

For those children who need products to manage incontinence problems then PromoCon can help here. PromoCon is a national service that promotes continence and product awareness and is based at Manchester's Disabled Living Centre, a registered charity. PromoCon has the national standing exhibition of continence products on the UK market and a confidential independent Helpline for any queries on any continence product: 0161 834 2001 open Monday to Friday 10-3pm.

Continence Awareness Campaign

PromoCon leads a Continence Awareness Campaign - 'Don't Suffer in Silence' which is active across North West England. The campaign is raising awareness about bladder and bowel leakage problems and works in schools, libraries and Healthcare Trusts. The taboo that surrounds these issues makes it hard for people to seek help and schools were highlighted as a key area to work to enable children to learn about healthy bladder and bowel practices such as drinking enough and not ignoring the call to stool, and address some of the taboos that make this subject difficult to talk about.

Three targets were addressed in the school campaign:

- school nurses
- teachers and nursery nurses
- the pupils themselves

Over 350 School Nurse Continence Resource Packs were distributed via the local Continence Nurse Service across the North West of England.

Teachers and Nursery Nurses themselves needed to have their awareness raised about bladder and bowel health and where to go for help (1 in 4 women and 1 in 9 men have a problem with continence at some point in their life).

Continence Specialists could not take on this education programme themselves in many areas due to their large clinical workload. However, providing resources, which could stand-alone could enable teachers to take up the issue with more confidence. Accordingly, a secondary school teaching pack with a Science and Personal and Social Education bias was developed - *Look After Yourself, Healthy Bladders and Healthy Bowels* and nearly 50 Lancashire schools have been sent the pack to trial. Initial evaluation appears to suggest that the pack is at the right educational level for children aged 11-14 in mainstream secondary education.

In the primary school it is also important that children receive the messages about bladder and bowel health. It was important that all children should have access to these messages where continence is potentially going to be achieved at any stage. The educational resources used in special needs education were studied. Many areas were using interactive learning resources that did not rely on text messages or only on the teacher's voice.

Development of interactive story packs promoting continence

The charity 'Bag Books' made resources like these designed for all ages with multiple and profound learning difficulties. Their Director, Chris Fuller, was open to working together with PromoCon to design resources to address key continence issues. Working with a team of local Continence Advisers in St. Helens and Knowsley the fundamental issues were talked over. Chris Fuller and Cate Parker, PromoCon Project Development Worker collaborated on the story line and Bag Books assembled the interactive packs. Testing and trialing found that the packs were fun for the children and achieved set learning outcomes. Launched at an ERIC National Conference in October 2001 the packs were received with enthusiasm and applause. Schools and Continence Advisory Services have started to use these packs.

What did the packs include?

The three multi-sensory packs are for different age groups and tackle a variety of issues. The stories are not in a conventional book form. Each 'page' is a sheet of A3 card to which is attached a single material or object for the listener to touch, hear, smell or see as the story unfolds. The story line is on a laminated card that is placed within easy view. This gives the storyteller the freedom to hand out the page cards to each listener or to enact the story to a group or class. The first pack that was produced was 'The New Boy' for junior mainstream children and this was produced to address the taboo that surrounds bedwetting. The second and most popular story with children is 'I'M TOO BUSY!' which is a story for infant children about ignoring the call to stool and constipation. The third storypack 'Jack's New Trousers' is for the older child with learning difficulties and how Jack is inspired to begin and become toilet trained.

In summary

Be aware that there is an independent information service on continence products available in the UK open to any caller - ring 0161 834 2001 or book an appointment for the Exhibition. We will be very pleased to help you.

Our Bag Book story packs on continence issues for children are available from Bag Books, 60 Walham Grove, London SW6 1QR Tel: 020 7385 4021.

Cate Parker
PromoCon
Project Development Worker

Addendum

With grateful thanks to Chris Fuller, Bag Books for her time and interest in the project and June Rogers, Paediatric Continence Specialist Nurse, St. Helens and Knowsley Primary Care Trust for her enthusiasm and support.

For More Information

On Medical Issues

for children and young people: ERIC Helpline, 34 Old School House, Britannia Road, Kingswood, Bristol BS15 8DB Tel: 0117 960 3060. www.eric.org.uk

for adults - Continence Foundation Helpline, 3007 Hatton Square, 16 Baldwins Gardens, London EC1N 7RJ Tel: 00845 open Monday to Friday 9.30-1 pm. www.continence-foundation.org.uk

On Continence Products

PromoCon Helpline, Disabled Living, 4 St. Chads Street, Cheetham Hill, Manchester M8 8QA. Tel: 0161 834 2001. www.promocon2001.co.uk

On the interactive story packs

Bag Books, 60 Walham Grove, London, SW6 1QR Tel: 020 7385 4021

report back

Oral Healthcare for People with Learning Disabilities: Problems, Priorities, Solutions

This one day conference was organised by the Royal Society of Medicine Forum on Learning Disability and took place on 20th february at the Royal Society of Medicine, London.

Guidelines on oral healthcare have been produced by the Faculty of Dental Surgery of the Royal College of Surgeons and the British Society for Disability and Oral Health in response to research studies which revealed shortcomings in the quality of oral care of people with learning disabilities and difficulties in accessing suitable services. These guidelines formed the background for the conference which addressed key themes related to oral healthcare.

Session 1 - Essential Healthcare for people with learning disabilities: Introduction to the morning. *James Hogg, University of Dundee*

The disengagement of medical professionals as key determiners of services received by people with learning disabilities since 1970 with the movement towards community care, has unwittingly resulted in neglect of their healthcare needs. Health needs were seen as being no different from those of the general population, and both general medicine and dental health were met by primary healthcare providers.

However, it is now recognised that people with learning disabilities have increased healthcare needs as compared to the general population, particularly where a person has a specific syndrome such as Down Syndrome, or complex impairments as in the case of PMLD. This issue is now receiving attention from both research and service providers.

Both general medical and dental providers did not provide adequately for this population for a number of reasons: inadequate training for doctors and dentists; lack of specialist support for their work with members of this population; contextual problems in relation to communication, and management of challenging behaviours; and referral problems as a result of lack of knowledge of family and professional carers.

In recent years with the acknowledgement of this situation there have been an increasing number of initiatives to improve this situation and ensure high quality healthcare provision for this particularly vulnerable population.

Session 2 - Oral healthcare guidelines and integrated care pathways. *Iona M. Loh, Barnet, Enfield and Haringey*

The Royal College of Surgeons and the British Society for Disability and Oral Health recognised the need to provide clinical guidelines and care pathways for those involved in service provision and/or caring for people with learning disabilities to improve the oral health of those in their charge.

The *Clinical Guidelines and Integrated Care Pathways of Oral Care for People with Learning Disabilities* was published in 2001. It was developed by a panel comprising members of the dental team, a family carer and voluntary sector representatives.

Sections of the *Guidelines* cover practical help and advice to parents, carers, healthcare professionals and the dental team on improving the oral health of people with learning disabilities, and how to overcome some of the common problems. They also illustrate ways in which those in influential positions can effect change.

The speaker described the development of the *Guidelines* and how recommendations are being implemented throughout the UK.

Session 3 - Problems and solutions - what has changed? Janet Griffiths

The speaker described her experiences of working with people with learning disabilities over 30 years. Her first experiences were in large institutions where emergency dental care was the rule. Special care dentistry, such as training in the specific problems associated with developmental anomalies, impaired oral function, medical problems and oral side-effects of medication, did not exist, and there was a real sense of professional isolation.

The changing philosophies and attitudes of the 70s, culminated in the move to care in the community, and the use of community dental provision. Barriers to access created by dental professionals were the result of low confidence, lack of experience of learning disability and financial limitations of the NHS. Professional training in special care is starting to address the needs of the dental team with greater awareness and understanding of specific oral problems associated with learning disabilities. Unfortunately nurse training in oral hygiene is reported to be inadequate and few formal carers receive training to support clients with oral hygiene and dental attendance.

Parents carers and professionals need access to information, support and training. Resources need to be increased for treatment and education. Access to care under general anaesthetic and sedation must be protected to reduce waiting times. Services must respond to the needs and demands of people with learning disabilities, parents and carers.

Session 4 - Preventing problems at an early stage and accessing dental services. Selina Harris, Epsom and ST. Helier NHS Trust

This speaker started with a review of the variations in oral health, and went on to cover preventive regimes and the advantages of integrated care. She considered Orthodontics for people with learning disabilities, and finished with some recommendations of the delivery of oral health education.

The second part of her paper reviewed the different types of dental services, what they provide, and how they can be accessed.

Session 5 - Consent to treatment - who can consent? Sue Greening, Gwent Healthcare NHS Trust.

This speaker spoke of the legal and professional complexities of consent. It is important for the individual to have the right to determine what happens to their own bodies. It is important for professionals and carers because of the liability for legal action for negligence or battery, if they do not act appropriately. The lack of English statute relating to consent has now been changed by the Human Rights Act (2000), but who can give consent?

Only an individual him/herself can truly give consent, but there are a number of problems. For consent to be valid it must be given by:

- a 'competent' person i.e. one who can understand to what he/she is agreeing;
- an adequately informed person;
- a person acting voluntarily and not under the influence of another.

These pose a number of questions:

What is a competent person?

When do we need consent?

When is consent voluntary?

How much information is required?

Who should seek consent?

When should it be sought and in what form?

How long does it last?

These questions are particularly important in relation to people with learning disabilities who have often been given little choice over the treatment they have received. The speaker considered the principles of consent for adults and children, and particularly for those people with limited ability to understand some of the procedures proposed as part of oral care. Some suggestions were made relating to good practice and these were illustrated through a number of case studies.

Session 6 - Profound and Complex disability: a family's perspective. Cathie Heaney, PAMIS, Glasgow

The healthcare of people with profound and multiple learning disabilities is of prime importance to their parents and carers. The complexity of their healthcare and the fact that many people with profound learning

news.....news.....news

NEW FUNDING FOR THE CREDO PROJECT

The Circles Network CREDO Project has been a 2 year national project that has focused on the lives of disabled teenagers perceived as having profound and complex impairments. The project has supported young people and their families through developing a 'circle of support' around them and by facilitating the approach of person centred planning that ensures that each young person has a plan that truly represents who they are as an individual, their dreams and goals in life. In addition they have the commitment of those who care about them involved in moving things forward with the ultimate aim of having a meaningful and desirable future.

Although every young person is completely unique, the original CREDO Project found a number of common issues that affected young disabled people who require high levels of support. These included:

- severe isolation
- a lack of friendships with other young people
- a need for support at meetings and reviews to counter the intimidation often felt by young people and their families
- inappropriate residential support
- inappropriate day support
- professionals taking over the process of planning and making decisions, without meaningful consultation with the young person and those who know him/her best

The CREDO Project works in direct collaboration with the young person and their family or circle of support and then alongside other agencies.

Circles Network have been extremely fortunate to have received a further three years funding from the Community Fund to continue and develop the CREDO Project in the Eastern region of England. The area to be focused on includes: Suffolk, Norfolk, Cambridgeshire, Peterborough, Essex, Luton, Southend-on-Sea, Thurrock, Hertfordshire, Bedfordshire. The new Project will also focus more on facilitating the development of friendships between teenagers with high levels of support needs and their non disabled peers and will host a national conference in year 2. The project will officially begin in the late summer of this year and if anyone would like further details then please contact the Circles Network head office on frances@circlesnetwork.org.uk - tel: 0117 373 7010 or fax: 0117 373 3011

Or alternatively contact the project co-ordinator - Nadine Jay after August on Nadine@circles.free-online.co.uk - tel: 01733 551253 or fax: 0870137 6585

www.circlesnetwork.org.uk

THE FOUNDATION FOR PEOPLE WITH LEARNING DISABILITIES

has moved to:
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Fax: 020 7802 0301
E-mail: fpld@fpld.org.uk

We are setting up a new programme into meeting the mental health needs of young people with learning disabilities and are currently advertising the criteria for research proposals to be funded as part of this programme. If you are likely to be interested in the area of service delivery to young people with learning disabilities and mental health problems, please look at our website www.learningdisabilities.org.uk where the details are posted. Alternatively please contact us on 020 7802 0350 or e-mail: fpld@fpld.org.uk to receive the same information by post.

SPIRITUAL NEEDS OF PEOPLE WITH LEARNING DISABILITIES MUST BE ADDRESSED

A new report from the Foundation for People with Learning Disabilities, part of the Mental Health Foundation, concludes that much more should be done to address the spiritual needs of people with learning disabilities.

A Space to Listen by Dr. John Swinton of the University of Aberdeen, states that although services currently aim to cater for people's physical and occupational needs, spirituality has so far been a neglected area. Dr. Swinton's consultations with family carers, service providers and people with learning disabilities themselves showed that this is, in fact, very important to people. In the report, spirituality is broadly defined as that which gives meaning and value to people's lives, which can include religious faith and culture, but is also a much broader concept. An example of what this can mean for an individual is the experience related in the report by a care worker. While out in the countryside with a boy with learning disabilities, he half-ignored the boy's shout of "it's beautiful" and continued chatting with his colleague. It was only when the boy shouted again that he paid attention and saw that he was describing the sunset. Sitting quietly together and watching the sunset enabled him to share an experience which, he feels was spiritual for both himself and the boy, and which, importantly, was identified by the boy, rather than the support worker.

"People with learning disabilities are socially marginalised, and the opportunities for them to be supported to find meaning in their lives can be severely limited," said Hazel Morgan, head of the Foundation for People with Learning Disabilities. "Meeting people's spiritual needs is essential if person-centred care is

to have any real meaning. The Foundation would like to see both services and faith communities enabling people with learning disabilities to experience and explore spirituality."

A Space to Listen stresses that spirituality is not just about enabling people to attend mosque or church or some other religious place, but is about care staff becoming open to the spiritual experiences that people may have. The research found that support workers are generally not equipped to recognise and respond to people's spiritual needs and that faith communities could often do more to be inclusive of people with learning disabilities. The report also suggests that friendship is one important and simple way of experiencing spirituality, and that this has implications for the concept of professionalism, which usually involves a degree of distance between worker and client.

Recommendations include:

- Agency policies need to address ways of meeting spiritual needs and to provide staff with training how to do this.
- People with learning disabilities should be given accessible information to help them make informed spiritual choices - although religious views must never be imposed.
- People with learning disabilities must be supported to make and sustain meaningful friendships.
- Faith communities need to be aware that there is much they can do to help meet the spiritual needs of people with learning disabilities, but should also be aware that certain religious practices can exclude people.

A Space to Listen is the first stage of the Foundation for People with Learning Disabilities' extensive research programme concerning spirituality and learning disability. Dr. John Swinton is currently carrying out major research for the Foundation, consulting people with learning disabilities and their carers about the nature of spiritual needs and how they can best be met. This will lead to the publication of a report and guidance materials in 2003. The Foundation has also funded Dr. Chris Hatton, of Lancaster University, to develop and pilot staff training materials on how services can meet the religious needs of people with learning disabilities.

Hazel Morgan added: "This is an exciting and innovative area of research, and one which has the potential to affect profoundly not only the lives of people with learning disabilities, but also those who care for and work with them. There is much that can be learned about spirituality from people with learning disabilities, and we are realising how much can be gained from engaging with this aspect of people's lives."

The Report was launched at a seminar in January and is available for £15 from the Foundation for People with Learning Disabilities 020 7535 7400 or through the website www.learningdisabilities.org.uk

reviews ... reviews ... reviews ... reviews

Developmental Movement for Children

Written by Veronica Sherborne

First published 1990 by Cambridge University Press

New Edition published by Worth Publishing Ltd. 2001

The new edition of Veronica Sherborne's classic book "Developmental Movement for Children" is to be welcomed, as it remains a seminal text for those engaged with teaching movement to children, with or without learning difficulties. There are very few changes or additions from the original edition, published in 1990, and in that sense there is no need for anyone who has the original to rush out and buy a new copy, since apart from some new photographs of children engaged in relationship play and a page of comments from practitioners, the book remains unaltered. It is clearly written and accessible, though anyone wishing to start up Sherborne work would be advised to attend training first, as the work needs to be experienced.

For those who have movement experience this book is a valuable resource, particularly when used in conjunction with videos of Veronica's work. Firstly the book gives a comprehensive explanation of the many Sherborne activities, and secondly, and perhaps more importantly, it outlines the fundamental principles behind her work. An understanding of the latter enables the talented movement teacher to create his/her own material as well as to use Sherborne's activities in imaginative ways. 'Developmental movement' sessions in special schools today are sometimes rightly criticised as being a rather routinely performed series of exercises. Perhaps this is because the teachers concerned have focused too much on a rigid adherence to the content per se without sufficient consideration of the gems of wisdom, which underpin Sherborne's work. For teachers this is not just a book to be dipped into when looking for material when planning lessons, but one that presents a philosophy of human development, whilst for parents it gives permission and confidence to physically engage with their offspring.

On first analysis this book has less to offer to those who have profound and multiple learning difficulties than other groups, as the number of activities within their grasp is more limited. Activities most appropriate to the PMLD population are easiest to achieve with the young, when size and weight do not cause problems, and include cradling, supporting, bouncing rocking, rolling, swinging, sliding and see-saws. What the book also offers, however, of great relevance to the PMLD population are Veronica

Sherborne's insights into the importance of human contact and the positive effect it has on learning, the essential need to form relationships before other learning can take place, and the positive influence acquiring body mastery has on forming self-respect. In the decade that has elapsed since Veronica Sherborne wrote this book, many changes have occurred in special schools including the introduction of the National Curriculum, clearly defined lifting and handling regulations, and mixed ability groupings. Read today this book is of great relevance to those working in special education if it challenges them to consider to what extent the current population of youngsters with PMLD have the chance to experience physical human contact, and to learn through touch.

As is pointed out in the excellent forward to the second edition, the book is written in "the language of the time" and some terminology has since changed to become politically correct. If a little dated in that sense, it is nevertheless just as relevant today as it was in 1990 and is certainly an excellent read for caregivers, teachers, parents and policy makers in the field of special needs.

Helena Rodwell

Dance and Movement Specialist for Special Needs

Enabling Access: Effective Teaching and Learning for Pupils with Learning Difficulties (2nd Edition)

Edited by Carpenter, B., Ashdown, R. & Bovair, K. Published by David Fulton 2001

It was a pleasure to be asked to review the second edition of this important book for PMLD-Link. Many readers will be familiar with the first edition which, soon after its publication in 1996, became accepted as a key text in the field of the education of children with learning disabilities, having won the 1996 NASEN Academic Book Award.

This book, it must be understood, is not primarily aimed at the teaching and learning of pupils with profound, multiple learning disabilities. It does however, address the issues, pertinent to all of us concerned with the education of such children, of access to the curriculum - in relation to both the National Curriculum and the wider curriculum in terms of process and delivery. There is one chapter (17) which specifically addresses the needs of pupils with profound and multiple learning difficulties.

The book is divided into 3 sections; Perspectives on the National Curriculum; Access and Entitlement to the Whole Curriculum and The Context of the Whole Curriculum. The chapters in Sections 1 and 3 cover essentially the same areas as they did in the first edition. Section 2 on the other hand has an additional chapter on PSHE and Citizenship whilst losing the chapter on Co-ordinating the Whole Curriculum. The book gains 50 or so pages in its revision. There are some changes in authorship of specific chapters and some 5 new names - and some losses. What all this amounts to is that although the book is virtually identical in format, there are significant changes to the content which would make it a worthwhile purchase if you found the first edition useful.

This title remains one of the most important publications considering the education of pupils with learning difficulties. It does not try to provide a "how to do it guide" on classroom practice or tips on the production of learning targets but it does provide comprehensive advice and guidance on provision of the curriculum to pupils with special educational needs across a wide continuum. This book provides us with the whys and wherefores of curriculum delivery - and as such should be on the bookshelf of all schools concerned with the education of children with special educational needs; including those with profound and multiple learning disabilities.

Suzie Mitchell
Educational Psychologist

NEW BOOKS AND RESOURCES

Developmental Movement for Children written by Veronica Sherborne. First published 1990 New edition published by Worth Publishing Ltd. 2001 This book is reviewed above.

Enabling Access: Effective Teaching and Learning for Pupils with Learning Difficulties (2nd edition) Edited by B. Carpenter, R. Ashdown and K. Bovair. Published by David Fulton 2001 This book is reviewed above.

Support Partnerships: Collaboration in Action. Written by Dr. Penny Lacey. Published by David Fulton Publishers 2001.

No Ordinary life: The support needs of families caring for children and adults with profound and multiple learning disabilities produced by Mencap 2001
Mencap, 123 Golden Land, London EC1Y 0RT Tel: 020 7454 0454 www.mencap.org.uk

A Space to Listen: Meeting the spiritual needs of people with learning disabilities. Written by Dr. John Swinton. Published by Mental Health Foundation. 20-21 Cornwall Terrace, London NW1 4QL. Tel: 020 7535 7400 e-mail: mhf@mhf.org.uk website www.mentalhealth.org.uk

Hello You! A Circles Network Video (46 minutes)

This film covers the following areas: Circles of Support; Direct Payments; Growing up; Communication; Supported Employment; Inclusion and Friendship; Person Centred Planning; Personal Assistants; Death of a Child.

Circles Network, Potford's Dam Farm, Coventry Road, Cawston, Rugby CV23 9JP
Tel: 01788 521078 e-mail: mandy@circles.domon.co.uk

Misplaced and Forgotten produced by the Foundation for Learning Disabilities.

Report of research based on a survey of 530 residential homes for older people and 53 offices responsible for registration and inspection of nursing and care homes.

Free research summary from: Foundation for People with Learning Disabilities publications office: tel: 020 7535 7441 or the website www.learningdisabilities.org.uk.

More information about the research from David Thompson, tel: 020 7535 7421 or e-mail dthompson@fpld.org.uk

I'm Too Busy; Jack's New Trousers; The New Boy - three New Multisensory Packs Promoting Continence. Devised by Bag Books and Promocon. Available from Bag Books, 60 Walham Grove, London SW6 1QR Tel: 020 7385 4021 e-mail: bagbooks@appleonline.net

COURSES AND CONFERENCES

MAY

9th

Sleep Difficulties in People with Learning Disability

An overview of contemporary research and practice in the area of sleep disorders and their management in this special population. Formal research studies, clinical experience and carer perspective. Open forum discussion.

Organised by: Royal Society of Medicine Forum on Learning Disability

Venue: Royal Society of Medicine, London

Further details: Melanie Armitage

Tel: 020 7290 3934

e-mail: learning.disability@rsm.ac.uk

www.rsm.ac.uk/learning.disability

14th

Sexuality and Personal Relationships

An introductory course aimed at anyone wishing to develop awareness and understanding of sexuality in people who have learning disabilities.

Organised by: BILD

Led by: Paul Eggett

Venue: Birmingham

Further details: Liz Howells, BILD

Tel: 01562 850251

e-mail: lizh@bild-edn.demon.co.uk

14th

NAIDEX 2002 Exhibition

Healthcare and rehabilitation equipment, conference and seminar programme.

Organised by: Touchstone Exhibitions and Conferences Ltd.

Venue: National Exhibition Centre, Birmingham

Further details: Maria Lenaghan, Touchstone

Tel: 020 8332 0044

e-mail: naidex@touch-stone.co.uk

21st

Parents - their perspectives of their child's disability

This course aims to give participants insight into the process that parents go through on hearing the news of their child's disability. It will focus on how parents find it hard to 'let go' and consider the service providers' role.

Organised by: roc

Venue: Harperbury, Herts

Further details: roc (resource for opportunity and change)

Tel: 01923 663628

e-mail: michele@hnhsroc.demon.co.uk

JUNE

5th

Assessment in the Curriculum for Pupils with Learning Difficulties

This course explores assessment for individual pupil's needs within a whole curriculum context. It will explore ways in which pupils' learning priorities may be identified and how these may be incorporated alongside assessment of achievement and attainment. The course will also consider the role which the pupils may play in their own assessments and in determining learning needs.

Organised by: Sunfield Professional Development Centre

Led by: Dr. Richard Rose

Venue: Sunfield Professional Development Centre

Further details: Sunfield School

Clent, Stourbridge DY9 9PB

Tel: 01562 883183

12th

Inclusive Play Training

A training day to find out more about developing inclusive play.

Organised by: Action for Leisure

Venue: Resource Centre, Moreton Morrell, Warwickshire

Further details: Nicola Burrows

Tel: 01926 650195

e-mail: Nicola@actionforleisure.org.uk

18th to Communication through Drama
A course for anyone working with people with learning disabilities who would like explore the benefits and practical use of drama in working alongside people with learning disabilities in creative and fun ways to encourage self-expression.
Organised by: BILD
Led by: Linda Mawson
Venue: Birmingham
Further details: Liz Howells, BILD
Tel: 01562 850251
e-mail: lizh@bild-edn.demon.co.uk

29th A Week of Celebrating Families
A week of day courses for Siblings, Grandparents, Mums, Dads plus a 1-day Conference for Professionals.
Organised by: Sunfield Professional Development Centre
Contact a Family
West Midlands Autistic Society
Venue: Sunfield Professional Development Centre
Further details: Sunfield School
Clent, Stourbridge DY9 9PB
Tel: 01562 883183

JULY

2nd and 3rd Cultural Issues in Sexuality Work with People with Learning Disabilities
This course will explore different cultural attitudes towards sex education and people with learning disabilities within services as well as the practical implications of carrying out sexuality work with service users from a range of cultural backgrounds within an equal opportunities framework.
Organised by: Consent
Led by: Seema Malhotra
Venue: Harperbury or Brent
Further details: Consent
Tel: 01923 670796
e-mail: consnt@hnhsrc.demon.co.uk

5th Guiding the Senses
To discuss and disseminate information on the use of multisensory rooms, legal and ethical issues, standards, training and research.
Organised by: Multi Sensory Environment Advisory Body (MSEAB) and School of Occupational and Physiotherapy, UEA
Venue: University of East Anglia, Norwich
Further Details: Robbie Meehan, School of OPT, University of East Anglia
Norwich NR47TJ
e-mail: r.meehan@uea.ac.uk

10th and 11th Intimate Care
This 2 day course will explore current practice and discuss key issues on the provision of personal and intimate care for young people with learning disabilities. The course will cover staff responses to challenging situations placing procedure within current legal and policy practice. There will be opportunity for problemsolving and teamwork.
Organised by: Sunfield Professional Development Centre
Led by: David Stewart and Steve Carnaby
Venue: Sunfield Professional Development Centre
Further details: Sunfield School
Clent, Stourbridge DY9 9PB
Tel: 01562 883183

12th Sherborne Developmental Movement - Level 2
 To allow participants to extend and reinforce knowledge gained during and subsequent to Level 1.
 Organised by: Sunfield Professional Development Centre
 Sherborne Foundation
 Led by: Cyndi Hill and George Hill
 Venue: Sunfield Professional Development Centre
 Further details: Sunfield School
 Tel: 01562 883183

SEPTEMBER

16th BILD Annual Conference 2002 - A life like everybody else
 to The Conference for 2002 focuses on the four key principles of rights,
 18th independence, choice and inclusion as outlined in the White Paper 2001 Valuing
 People. The conference theme A Life Like Everybody Else explores these key
 principles in a practical and participative way.
 Venue: Imperial Hotel, Torquay
 Further details: Liz Howells
 01562 723016/723010
 e-mail: l.howells@bild.org.uk

24th Cultural Issues in Sexuality Work with People with Learning Disabilities
 and This course will explore different cultural attitudes towards sex education and
 25th people with learning disabilities within services as well as the practical implications
 of carrying out sexuality work with service users from a range of cultural
 backgrounds within an equal opportunities framework.
 Organised by: Consent
 Led by: Seema Malhotra
 Venue: Harperbury or Brent
 Further details: Consent
 Tel: 01923 670796
 e-mail: consnt@hnhsroc.demon.co.uk

OCTOBER

31st Special Needs London
 to Venue: Business Design Centre, Islington
 2nd Nov. Further details: Publishers Association
 Tel: 020 7691 9191
www.publishers.org.uk

20th Rehab and Care
 and Venue: NEC Birmingham
 21st Further details: 00870 429 4372

BILD Workshops and Conferences

These cover a wide range of topics including:

Understanding Autism	Developing policies in management of challenging behaviour
Understanding Challenging Behaviour	Person Centred Planning
Sexuality and Personal Relationships	Putting the Learning Disability Awards Framework into Practice
Exploring Creative Ways of Working	Life Story Work
Mental Health	Risk Assessment Management
Communication Through Drama	
Physical Interventions - Code of Practice	

All these courses are held several times throughout the year in different parts of the country. For the schedule and further details contact Liz Howells 01562 823016; e-mail l.howells@bild.org.uk

OPEN DAYS

Action for Leisure Resource Centre Open Days:

Low cost Multisensory Room; Wide selection of toys, games and equipment; Small items to purchase; Database of information; Reference library of books, videos, journals and publications; College farm animals; Garden centre.

Refreshments; disabled toilet on site; parking space for disabled drivers

Open between 9.30 am - 12.30pm or 1.00 pm - 4.00pm.

Wednesday 1st May

Thursday 16th May

Friday 7th June

Saturday 22nd June

Monday 1st July

Tuesday 23rd July

Booking form from:

Action for Leisure, C/O Warwickshire College, Moreton Morrell, Warks CV35 9BL

Tel: 01926 650195

LONGER COURSES (with accreditation)

Interdisciplinary work with People with Profound and Multiple Learning Disabilities

A one year distance education course for practitioners and carers of children and adults with profound and multiple learning disabilities. The main focus is upon lifelong learning, communication and effective interdisciplinary collaboration.

Offered at three levels: Post experience certificate (level 1), Advanced Certificate (level 3), Post graduate diploma and Masters (level M)

University of Birmingham School of Education

Further details: Sandra Cumberworth Tel: 0121 414 3466

M.Sc/PG Diploma in Learning Disability Studies

1 year full-time or 2 year part-time course.

This course meets the training needs of a variety of professionals involved in delivering services to children or adults with a learning disability, including registered nurses, social workers, doctors, occupational therapists, physiotherapists, speech and language therapists, officers in statutory, voluntary or private establishments, FE tutors, staff of SECs. It provides the opportunity to participate in and contribute to inter-disciplinary learning in a collaborative setting.

Further details: Helen Bradley Tel: 0121 678 2353

Profound Learning Disability and Multi Sensory Impairments

A two year course for parents, carers and professionals which will develop skills and obtain recognition for them. Work is home based, supported by workshops and telephone tutor support. Issues relating to challenging behaviour, communication, education, ordinary life principles, sensory impairment, interdisciplinary working and epilepsy are addressed.

The course is offered at three levels: Certificate, Advanced Diploma and Masters.

University of Manchester Faculty of Education

Further details: The Programme Secretary, Educational Support & Inclusion,

JTI Office, University of Manchester, Oxford Road, Manchester M13 9PL

Tel. 0161 275 3337 e-mail: JTIOffice@man.ac.uk

Certificate in Working with People who have Learning Disabilities

Distance learning courses from BILD for staff working in the learning disabilities field.

All courses are accredited through the National Open College Network .

Better Health

Ageing Matters

Better Choices for People with Profound and Complex Needs

Induction to learning disability services

Foundation: communication

Foundation: abuse

Further details: BILD Learning Services

Tel. 01562 850251

PMLD-Link

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