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PMLD LINK

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

CONTENTS

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

EDITORIAL Autumn 1995

This issue of PMLD-Link focuses on *Promoting Independence* and, as usual, we have a number of different perspectives on this wide ranging subject. Promoting choice in different settings is a recurring theme, and it is interesting to see that two of the articles are firmly based in creative activities as a context for promoting independence. One of the articles challenges us to think about our own concept of what precisely, independence really means for people with PMLD and how this can be achieved in the broadest sense of the quality of life which a person can achieve with whatever support is necessary.

We are still receiving articles from people who work in other countries. In this issue we have an interesting account of the development of a service for children with PMLD in New Zealand.

The Conference held in 1994 at the University of Birmingham on Promoting Quality of Life for People with PMLD seems a long time ago now, but the handouts and overheads used by some of the speakers may still be of interest to readers. Two sets of these are included in this issue and the rest will follow in the Spring issue. They may help to prompt memories of the issues which were addressed that day.

The theme for the Spring number of PMLD-Link is *The Early Years* and in our FUTURE FOCUS section Barry Carpenter has written an article to set you all thinking about the importance of the early years, particularly for children with PMLD. In his article he looks at the draft of the new SCAA document on pre-school education and discusses many issues which are raised by this document as well as current practice in this vital period of early education.

Thank you to all contributors to this issue for finding time to write articles. Please continue to wite in about your own practice, useful toys or equipment, courses you have been to, books or anything which might be of interest to other readers. Articles etc. for the next issue should reach me by 4th March, but don't be put off by the date - write when you can and send it in!

Business Matters

This is the first issue of the new subscription year - 1995-96. Make sure you have renewed your subscription so that you will not be disappointed when the Spring number does not arrive! The subscription is still £6.00 for this year, but it is likely that this will have to be increased next year in order to cover the ever-rising costs.

Carol Ouvry

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Independence?...
That`s middle class blasphemy. We are all dependent on one another, every soul of us on earth.
G.B Shaw

Professionals have been training people towards `independence` for many years. O`Brien (1990) offers two definitions of independence. The first is the familiar rehabilitation model where people are trained to be able to meet their own basic needs with minimum assistance. The second is an independent living perspective which sees independence as choosing and living ones own lifestyle - regardless of the amount and type of assistance necessary. Independence would therefore not be measured by the number of tasks which people can do without assistance but the quality of life a person can have with whatever support they need.
He says that:
Independence is not measured by the quantity of tasks one can perform without assistance, but the quality of life one can have with help`

For people with profound multiple disabilities to `choose and live their own lifestyle` requires us to prioritise developing self advocacy and communication skills for each individual and change the questions we are asking. Instead of using assessments to measure skill deficit, we would ask questions such as:

- How can we increase the number of places in the community that the person goes to?
- How can we increase the number, variety and significance of the choices that the person is able to indicate?
- How can we increase the variety of the person's interests and are their opportunities to share these interests with others in the community?
- How can we increase other staffs` knowledge of the persons` interests and preferences?
- How can we increase the respect that the person is given?
- How can we improve the person's health?
- How can we provide better support for the persons existing relationships?
- How can we help the person to meet more non-disabled people?

and finally...
- Are there any skills that the person could develop that would increase their opportunities to participate in community activities, make more choices, be respected by others more and develop more relationships?

Asking these sorts of questions is obviously different from the way most people experience individual planning or reviews. There are other styles of planning, such as Essential Lifestyle Planning which focuses on identifying the choices and

lifestyle that the person wants and how we can support the individual successfully to achieve these. This and other styles of `person centred planning` put skill development and independence into the context of other factors which can improve the person`s quality of life.
Rather than asking whether it will increase the person's `independence` we ask if having that skill will enable the person to participate more, communicate more and develop more interests.

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Reference

O`Brien, J, (1990), Design for Accomplishment. Responsive Systems Associates, Georgia,

Creating a Music-Drama Event

We are constantly searching for valid, age-appropriate activities that engage the pupils and students, provide interest, enjoyment, clearer understandings, choices and dignity.

Combining music and drama together provides a rare opportunity in which all pupils can be included in a theatrical event and can participate at their own level. Every response from every pupil is equally valued and this makes the use of drama and music a useful tool for integration.

Those who have been involved in a GALAXIES performance will be aware of the impact it has on the pupils. It is dependent on the adults being fully involved in the event, to facilitate, to interpret, to share character parts, to bring to life a sequence of events which are the storyline, activities, sensory effects and songs. The science fiction theme is appealing and appropriate for all ages. What we have in GALAXIES is a model that can be incorporated into school produced music-drama events.

Before you sit down to write anything, get together with all the people who will be involved in the performance. The first two questions you need to ask are:

1. What themes are appropriate for primary pupils?
2. What these are appropriate for senior pupils?

Discuss these questions, and make a list. Choose your theme.

Having decided what the theme of the music-drama will be consider the skills and interests of the pupils who will be involved in the performance. List these, so that they can be incorporated into the storyline. The use of dramatic effects can underline and heighten the awareness of each pupil's contribution.

Now that you have a theme, a storyline and dramatic effects you may decide to include a song or two. This could be written around a particular activity/event in the performance. By especially writing a song you can include more responses from the pupils. It may be easier to record the storyline and song onto tape.

By now you will have a clear idea of the props you will need. Costumes help to place the individuals and staff in role, making it a truly dramatic event that is totally different from the rest of the timetable. Consider contrasting colours, shapes, sizes, textures, smells, sounds and tastes. Different lighting and back-drops may help to focus the pupils' attention.

When all this is in place have a trial run-through. There will be a lot of laughs while everybody attempts to remember what they have to do. Don't worry! You may want to pin the words of the song up on the wall. Try it through a

few times to iron out any difficulties. When you all feel it is running smoothly make sure that all your props, costumes etc. are stored carefully so that they are easy to reach.

Carrie Lennard

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Carrie Lennard has been involved in the teaching of pupils with severe and profound learning difficulties for many years as a class teacher, a music co-ordinator and as a learning resources co-ordinator. She is well known for her music publications: *Body and Voice : Funfair : Galaxies : Seaside : Caterpillar : Zoo Visits*. Due to an increased demand for her music skills and expertise she will be available to provide in-service training to staff working in SLD schools and establishments from January 1996. Please telephone 0181-560-1738 for further details.

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AUTONOMY AND INDEPENDENCE FOR CHILDREN WITH PMLD

Suzanne Saunders

The dictionary defines 'autonomy' as 'the right or state of self-government' or 'the freedom to determine one's own actions'; and 'independence' as 'free from control' and 'capable of acting on one's own'. Whilst we may agree that these are not only desirable states but fundamental rights for any child, the question of their applicability to children with profound, multiple learning difficulties (PMLD) poses many problems. As teachers we must be clear about exactly what independence might mean for a child who may not be able to walk, talk or control their movements effectively, and how they may display autonomy given their degrees of intellectual impairment. We must then go on to develop strategies to ensure that our pupils are given opportunities to develop these skills and to practise and demonstrate them in their daily lives.

There are many ways in which pupils with profound difficulties may demonstrate autonomy. At the simplest level they might express their likes and dislikes and indicate to us whether or not they wish to continue with an activity, enter a specific place or work with a particular person. As they develop, they might express preferences for one scenario over another, and make choices between two or more objects, people or events. This can lead to their initiating an activity or selecting a person to spend time with.

A person who is aware of a desire and can make it happen, and who can prevent something occurring that they do not like, can be said to be acting autonomously. How we plan our classrooms, our time, our teaching and our curriculum to develop this autonomy in our pupils should be one of our prime concerns.

Our first consideration, before we think about our pupils or their skills, should be to look at ourselves and to examine our own values and attitudes towards the children's independence and autonomy. The attitudes that we hold, and the attitudes of all the staff who come into contact with the children in our classes, are crucial as they will affect the ways in which we relate to the children, expect them to behave, plan their activities and carry out day-to-day tasks. It is worth spending time talking with our classroom assistants, the physiotherapists and the volunteer who comes in to help one morning each week, etc., to ensure that the beliefs and attitudes of all staff who are in contact with the pupils are such that their resulting behaviour will encourage and develop pupil autonomy.

Attitudes and values towards children with PMLD that will promote their independence include belief that:

- They are valued, important people who have a contribution to make.
- They have their own needs, preferences and desires, and a right to express them.
- They have a right to be taken seriously and afforded the dignity that is appropriate to their age.
- Autonomy and independence are curricular aims for all pupils.
  All pupils are capable of learning and developing, and that includes developing autonomy.

If we all adhere to these basic beliefs about our pupils with PMLD, we will expect them to respond in particular ways and will create an environment, plan activities, and relate to them in ways which will enable them to display and use their independence. We will expect them to:

- respond to our teaching and perhaps initiate activities themselves
- communicate with us in a variety of ways that we must learn to interpret
- be responsive to our attempts to develop and enhance their communication skills
- affect and influence their own lives, their environment and the people around them.

We must therefore be constantly evaluating everything that goes on in our classroom to ensure that the attitudes and values that we hold and speak of, are reflected in our practice, and evident in the way we relate to our pupils.

Developing autonomy and independence in pupils with PMLD is not a discreet activity that can be slotted into a couple of PSE lessons each week; rather it should permeate everything that goes on in the classroom and the goals should be pursued through everything that we do with the children. However, this may require us to reappraise our notions of who holds the power and exerts the control in our classroom. If we are trying to empower our pupils and encourage them to take control of their lives and their environment, we may have to relinquish some of the control we hold. Traditionally, the teacher in a classroom is a very powerful person who decides what will happen, when, how, and what the outcomes should be. I would suggest that we need to move to a position of shared control with our pupils, whereby both are prepared to control or be controlled, and to direct or receive direction as the situation demands. Consideration of how this power-sharing may be achieved, leads us to consider our teaching methods and approaches. The good teacher is aware of a variety of approaches, all of which are useful and effective at different times, with different pupils, and in order to teach or develop different things. However, some are more pupil-centred and lend themselves more easily to the development of shared teacher–pupil control.

The long-favoured objectives approach (Ainscow and Tweddle, 1988), whereby the teacher identifies a goal, identifies small steps that need to be achieved in the pursuit of this goal, and then teaches those steps sequentially and often in highly controlled circumstances, looking for very specific outcomes, may well have a place in the teaching of pupils with profound difficulties. However, it does little to encourage the development of autonomy as it is the teacher who decides what activities are to be engaged in, under what conditions and what the outcomes should be. There is no room for the pupils to change the course of the activity, or to produce a different outcome.

There are alternative approaches relevant to the child with PMLD which are more pupils centred and where pupils are encouraged to make individual responses and where those responses are received, acknowledged and acted on by the teacher, thus encouraging further pupil involvement.

Intensive interaction (Nind and Hewett, 1994) necessitates the teacher abandoning a formal teaching role and, instead, employing his/her intuitive abilities to interact and communicate with a child at the child's own level, employing a range of interactive games such as might be used by a parent and their baby. The teacher needs to be highly sensitive to the pupils and adjust his/her responses to engage the pupil's interest and emotional arousal.

Gentle teaching (McGee et al., 1987) with its notions of solidarity and empathy with pupils emphasises the making of partnerships with children, with all the dialogue and negotiation that that entails.

In her descriptions of Pupil Participation, Tilstone (1991) requires the teacher to develop in-depth skills of observation so that s/he can see the signals being given out. The teacher can then respond to the child's wishes even if they may be unwelcome or inconvenient, rather than seeking to dominate or override them.

Ware (1994) also emphasises the importance of the transfer of responsibility from teacher to pupil as she talks of partial participation whereby the teacher performs an analysis of a task relative to what the pupils is able to do with an without help. By identifying the control features of a task, it is possible to move to a point where the person with PMLD takes responsibility for reaching the goal even if they cannot perform at the mechanics of the actions involved.

All these teaching approaches emphasise the need for the teacher to relinquish a position of control and become highly responsive to the pupils in order to encourage and develop their ability to exert some measure of control and independence. It is not sufficient however merely

to 'look out' for a child's communications or attempts at initiation. Many of the children whom we teach will have learned passivity and introversion over many years and have learnt that their input is neither required nor desired. Situations must be specifically engineered to allow pupils to learn and practice these skills, and routine activities should be carried out in such a way as to encourage choice and decision-making. It is only when a child experiences his/her communications being responded to in a way that brings immediate pleasure or relief that s/he will begin to understand that his/her actions can bring results and will begin to move towards intentional communication. As s/he begins to initiate and expect responses, s/he is beginning on the road to autonomy.

It is very easy to find reasons not to respond to children in a busy classroom. Insufficient staff, lunch time, taxis, lack of equipment, the needs of other children all provide us with compelling excuses. However, if we are serious about empowering children we, and perhaps the whole school, must acknowledge that responding to children is a priority that is perhaps more important than adhering to institutional time-scales or routines.

In conclusion, one of, or perhaps the, most important aim of education for children with PMLD is to help them to become independent, autonomous citizens. We must constantly evaluate and reappraise our teaching to ensure that we are encouraging and enabling our pupils in this aim.

Questions that will help us might include:

- Do my volunteers really understand what we are trying to achieve?
- Is there any piece of equipment that would enable Amy to do that herself?
- Did any pupils make me change my plans or do something differently today?
- What choices can I give Jenny that will really motivate her?
- Am I trying to cover too much curricular content at the expense of interacting with pupils?
- Who was in control today?!

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NIND, M. and HEWETT, D. (1995) *Access to Communication.* London: Fulton.

TILSTONE, C. (ed.) (1991) *Teaching Pupils with Severe Learning Difficulties.* London: David Fulton.

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

For further discussion of some of these, and other ideas on Autonomy see:

COUPE O'KANE, J. and SMITH, B. (1994) *Taking Control.* London: David Fulton.

SEBBA, J., BYERS, R. and ROSE, R. (1995) *Redefining the Whole Curriculum for Pupils with Learning Difficulties* (2nd edition). London: David Fulton.

PROMOTING INDEPENDENCE THROUGH FURTHER EDUCATION

The 1992 Act brought enormous policy changes to the further education sector . The Act came into force in 1993 and in a sense created a system of adult education with characteristics in common with the opted out status of grant maintained schools following the 1988 Act . All colleges in England and Wales without the choice provided within the 1988 Act now have corporate status and are run independently of the Local Education Authority . The majority of the funding a colleges receives comes through the Further Education Funding Council based in Coventery on a system of units per accreditation .

All very interesting if this is news to you but what are the implications for PMLD adults in this new market led world ? The first clue is this notion of market led . A college of further education competes with its neighbours for students . Each college has each year been required to show efficiency savings and one measure of this could be more for the same cost . Certainly the government has been promoting independence , the theme of this edition of PMLD Link , but how can colleges provide this independence for what is a costly branch of education , PMLD ? Larger class sizes are no use in this area of teaching . Specialist computer peripherals for example are not cheap but are an intrinsic feature of PMLD teaching . Remember , the college has to buy the lot . In the new era of market forces the college pays for all its services from the Principal's salary to the gas bill . PMLD resource allocation has to be measured and allocated according to the wealth of the college . The wealth of the college very much is linked to the efficiency of its systems and the number of students . More students = more money .

Perhaps this sounds all too depressingly familiar ? Further confirmation of public sector cost cutting at the cost of reducing quality ? After all , one very crude definition of PMLD adults are those people at the periphery of the education system , those people whose needs are not met in traditional modes of teaching . They as a consumer group , (sorry for the term , lapsing into further education speak there) are not likely to be well represented or able to be vociferous in making their needs known . What chance have they in promoting independence within their lives in a system which is independent and very competitive ?

Well, surprisingly , if a college is innovative and structured to need then the picture does not have to be gloomy . I write this so that if you are interested you should approach your local college and find out what is going on . If they don't take in PMLD adults , ask why not ? Equal opportunities is just that , equal for all , not just the academic . So you approach the college and ask and they say no we don't accommodate PMLD , they are probably not heartless souls but have not appreciated how a college can help . No PMLD person is ever going to achieve independence if the process ends at school and further education has to play a vital role . Here's how a college can accomadate PMLD and this , suprise , suprise means going back to the funding mechanism . . A college receives it units per student if they are vocational accreditations . The FEFC and therefore the government have built into the vocational

system the Northern Programme of Record of Achievement (NPRA) which the person probably will have had experience of in school . An NPRA individual accreditation programme based upon a small measure of developmental skill is written , this could be as little as increased concentration span whilst operating a computer using a switch . This is promoting independence , building upon skills and achieving a process of learning that recognises and certificates life skills . No college has any excuse if they are not doing this because NPRAs are a recognised part of the structure the FEFC are willing to fund . Hats off to the FEFC in recognising a breadth of need .This is marvellous news for the PMLD adult , a process of learning that can continue into adulthood . There are limitations , the FEFC insist on progression, you have to move up a level a year but the system is in place . The cost ? Yes, PMLD adults often require a high level of support . Again , the FEFC have thought through this and though they will not pay for equipment they will pay for the support costs through an additional support unit scheme . And how about this , the additional support money is assigned to the individual who attracts the support, it should not disappear into a college budget never to be seen . In a sense it belongs to the adult because his or her needs have been costed into a service that is provided .

Truthfully, the whole picture is not all smelling roses but there is much good to be built upon . There is a thrust in the more imaginative colleges to promote not only its own sector independence but also the independence of PMLD adults . A college shapes its own policies separately to the LEA , no PMLD referrals means exclusion from their policies . We in further education have a service to sell and if you don't ask for it we will not provide it . It's no use me selling meat if everyone is vegetarian . So, if you are planning ahead , contact your local college and see what's on offer . Long gone are the days when it was the learning home for mechanics and plumbers . If they have nothing on offer , you now have the arguments . Good luck .

DAVID KITCHENER IS THE CURRICULUM MANAGER FOR SPECIAL NEEDS AT ACCRINGTON AND ROSSENDALE COLLEGE IN LANCASHIRE .

Networking through PMLD-Link

Don't forget that you can use PMLD-Link to ask for help and information from other readers when you are looking for ideas equipment and knowledge that others may have. Just write a short paragraph stating what you are looking for, and this can be put into the next issue of PMLD-Link. We send out 350 to 400 copies each time to people working in all kinds of services and from all professions as well as some parents. This should bring in some useful responses.

We would also be interested to know whether using PMLD-Link in this way has worked for you - just a postcard or a phonecall will be enough to tell us.

Self Advocacy through Drama

There is an argument which states that a person's life can be narrated through abstract images. Those images being invented by way of the vocabulary used in relation to the group. It is a complex argument, and would require more attention than this articles allows. However, at a much more basic level, the notion that people become what is expected of them is a much easier concept to accept. It is, in fact, one of the basic premises that I use when working on projects involving students with PMLD.

The project, which I will outline shortly, is one example of the way in which these students can acquire a 'voice' of their own. It is indeed a useful way in which the teachers of students with profound and multiple disabilities can endeavour to support the student in their search for autonomy and self-advocacy.

The project assumes the responsibility of looking at what students with PMLD can already do, or what they would be expected to be able to do in the short term future. It then aims to take these abilities and provide a framework which supports and enhances them, so that other people can recognize their achievements.

It is, in our view, vitally important to ascribe status to a person's present worth and not to demand that something, as yet unachieved, has to be attained before recognition is given. It is therefore seen as particularly important to create environments and vehicles which abidingly project positive images of our less able students. It also seems to be of equal importance that we allow their particular 'way of being' to accompany the variety of ways in which, as individuals, we all make our mark upon the community in which we live.

The project that I am about to describe is, broadly speaking, a drama project. The aims of the project, in addition to the statements already made, were to encourage a wide range of people, both within the school and the local community, to think about and to relate with those people who have profound and multiple learning difficulties. Of course, its main aim would be to offer something to youngsters who have these learning difficulties, which would be exclusively for them - no strings attached!

In order to cover all those aspects which would seem worth describing, I will give a very brief outline of the content of the production which the group are engaging in. I will then give a more detailed account of one or two scenes in order to summon up a flavour of the teaching content, to search out any recognisable advantages emerging for the group, and to talk about the ways in which we have tried to encourage greater integration within the school and the community.

The drama is set in a tropical forest. The opening scene sets the mood of the forest by depicting, as actively as possible, those features that you would expect to find there, plus a certain amount of creative license. Moving on, we find that there are two main protagonists, the birds and the woodcutters. The birds are, of course, using the forest in an ecologically sound way. The woodcutters are not. They are damaging the birds' chance of survival and in

fact one of the birds is seriously injured in the second scene, (a happy recovery is made, I hasten to add).

As the story proceeds, it emerges that the woodcutters need to chop down trees in order to earn enough money to live, and the birds, who at first thought they could solve their problems by figthting or running away, discover that neither of these solutions will work. What to do? Of course, a compromise is what is needed and the solution to the problem is provided by a mutual consideration of each of the others' needs.

To this end, the birds collect not only enough food for themselves, but enough to share with the woodcutters. This food provides the means to make money, other than by cutting down trees. The woodcutters sell their food at market, and the proceeds are used to buy themselves a boat, which is used to give tourists and visitors trips down the river. The main spectacle, which will probably come as no surprise, are the exotic and beautiful birds who dart skillfully and acrobatically through the trees.

Going back to the start of the drama where the scene is being set, there are many props which are currently being made in order to allow the youngsters to create dramatic action as independently as possible, by using skills currently available to them. On the following page there are some drawings which should give an idea of how such a scene might be enacted.

Within the group of students that we teach, we have quite a wide range of ability from those who are extremely isolated and very difficult to reach, through to those who are rather spirited and who have a developing awareness of themselves as individuals within the group. Certainly the activities above indicate that there are skills and concepts emerging here which allow people to take a more active part in general relationships and encounters.

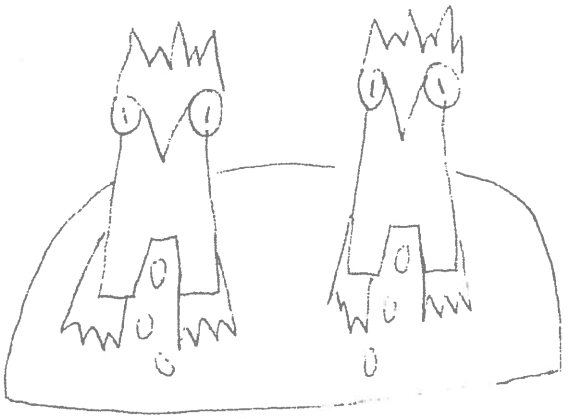
Other scenes place importance, or focus more upon those individuals who have great difficulty in coming to terms with themselves and/or their environment.

Scene three and scene nine show evidence of this endeavour. In scene three, which is entitled 'The March of the Woodcutters', a lot of preliminary work is being done on responding emotionally to situations. The idea is that through music, mood setting, and physical interaction, we will be able to give those most distant youngsters a chance of coming closer to themselves, to their peers and to the adults in their lives.

In order to capture these moments, which quite possibly will only be fleeting and transitory, we will take many sessional photographs. On the day of the production, these images will be shown in the form of slides, projected onto a backdrop, while the action is taking place.

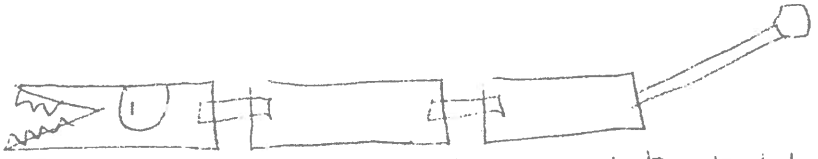
Each scene has been developed to enhance the visual impact of the youngsters' achievements. In scene nine, where the birds have lost heart and are unable to imagine how they can save themselves, the action is stated entirely from sitting. As I said earlier, it focuses on the most distant youngsters, in the sense that on each side of them is an adult who is helping

them to move rhythmically to music. In my experience, there has not been any youngster, however distant, who does not respond positively to some form of movement interaction.

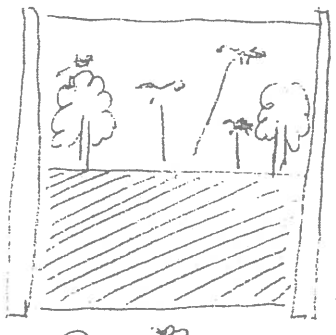


Two model birds on raised nesting area:- Youngsters post the 'eggs' through holes made in the back of the birds.

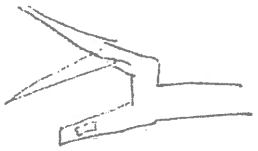
large bird attached to very stiff, folded cardboard: Youngsters 'push' the bird so that it rocks from side to side



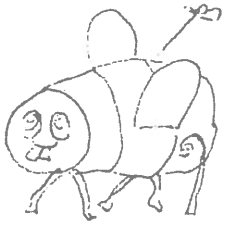
Junk cree, with rod attached to hold on to: Youngsters hold the stick while their chair is pushed or pulled.



½ covered puppet screen: Youngsks hold up stick puppet trees, while other hold stick pupper birds, moving them about to fly through the air.



Talking bird: Youngsters press thumb up towards their fingers to make the bird talk



Egg box suspensions: Youngsters touch them and they move about

paper plate faces: two plates stuck together with opening at back.

finger puppets at table: Youngsters try to keep their hands still

Almost all of the action is described by the youngsters themselves.This narration takes the following forms:

a) hand held placards, which pictorially describe an set each scene:

b) character representations, again in the form of hand held placards;

c) the use of speech synthesizers, such as the orac, which can be activated by a touch

d) the use of the youngsters' own voices, where that is possible.

In this way the control of the drama resides with the students and not with their enablers.

Coming now to the aspect of integration. We have looked at the way in which technology might be an advantage to the independence and autonomy of the individual with profound learning difficulties and have approached relevant groups such as media studies and a variety of college courses in order to ask them to become involved with our students.

So far we have the possibility of a professioally edited video lasting five minutes. This would be included in the live production. Art courses are interested in making a selection of props and other more able youngsters within the school are thinking about how they could help our students.

The on-stage production will vary from other productions in that there will be adults on stage, supporting students in their attempts to create this drama. It will also differ very much from the conventional setting in that there will be verbal encouragement where necessary. In this way it might be quite possible to see or hear an adult speaking to a student on stage. However, we feel certain that the overall impression will be that of students who are keen to be involved, who are enjoying the experience of doing something for other people, and who are visibly uplifted by this small opportrunity for self discovery and self-advocacy.

The purpose of the project, as stated at the outset of this article, was to support youngsters' current abilities and to use these abilities in ways which enhance their image. This image enhancement may take many guises, from a simple change of perception, to the offer of some form of mutually beneficial integration within the community. The end result is of less importance, however, than the fact that these young people will have been 'speaking' for themselves, will have been 'witnesses' to their own talents. They will, in so many ways, have been their own best advocates, who by their own means will have alerted us to their existence and to their importance as individuals within our community and within our lives.

Chris Wilkinson, Mayfield School, Villa Street, Lozells, Birmingham.

Service Delivery to Children under the Psychopaedic Initiative: A Psychologist's Viewpoint

History of the Psychopaedic Initiative

The introductin of the 1989 Education Act in New Zealand gave all children and young people the right to education services. This had enormous implications for those children and young people who were in residential care in Psychopaedic hospitals and at IHC and CCS preschools who had previously been denied access to schooling. The Psychopaedic Initiative came into being to identify, assess and provide placement into appropriate school facilities.

In the Auckland area Manukau Special Education Service played a major role in this, and now has the contract to provide services to those young people under the Psychopaedic Initiative over the greater Auckland and Northern areas. This has required a tremendous effort, and increasingly so now that associated therapy staff are employed, and when one considers that initially the children were in 4 facilities and are now in 19 facilities (as from 20.1.93)

Outline of therapy services

Each Special Education Service (SES) area across Auckland with psychopaedic children has been allocated speech language, physiotherapy, and occupational therapy services. There is also a very talented music and art therapist who, like myself, works across three or more different SES areas. In my case this is because I work in four special schools and these are in three different SES areas. This means that I am part of three different teams.

In South Auckland (Manukau) we meet as a group every 4-6 weeks together with our area co-ordinator. Our individual area teams also meet once every 2-3 weeks. These team meetings have been invaluable for sharing caseload numbers, discussing problems with individual children, and providing collegial support for some of the major issues which have arisen. These points will be elaborated in the description of the way the Initiative works.

Description of caseload

My caseload comprises 51 young people spread across four special schools (see Table 1). One school had considerably more young people as it was situated across the road from the Mangere Psychopaedic Hospital.

It is worth noting that the young people fall into 2 dsistinct age groups, 50% of these have multiple disabilities, and all of them could be classified into what Presland (1989) describes as children with profound and multiple handicaps (PMLD). He defines PMLD as those who have "so many learning difficulties that they are totally dependent on others. Typically, they speak no more than a few words and understand very little that other people say, have difficulty manipulating objects beyond infant level and are unable to dress themselves or attend to their toilet needs without supervision. If, in addition, they have severe physical or sensory handicaps, we say they have profound and multiple handicaps. Such people commonly have severe problems of

behaviour, and these are particularly difficult to manage, let alone overcome, if the people showing them are mobile."

Table 1: Caseload distribution across schools, age group and multiple disability

Schools	A	B	C	D
5-12 years	10	5	4	6
16-21 years	17	2	5	2
Multiple Disabilities	14	3	6	3

Formulation of role as psychologist

Presland (1989) also outlines current advances in curriculum ideas and how to introduce new developments, and solutions to overcome many problems inherent in this area from the point of view of a psychologist. The problems he discusses include devising an appropriate curriculum, identifying teaching tasks, guiding the learning, reinforcing the learning, identifying appropriate behaviours to replace problem behaviours, identifying changes in antecedents and consequences likely to decrease a problem behaviour, and managing resources for most effective action.

I also participated in a university seminar for trainee psychologists on the role of psychologists in special schools. As part of this seminar we had a forum panel consisting of 2 principals of special schools, 1 parent, and 2 psychologists. The results from this forum are outlined in Table 2.

It is interesting to see the overlap in areas such as assessment, placement, and resourcing, but a competing issue arose between the psychologists wanting a partnerhsip/co-ordinating role and the special school principals wanting a more hands on/training role. It appeared that psychologists in these schools had been available for IEPs/staff training/challenging behaviours on a needs basis, but were rarely available in a hands on, working alongside staff and demonstrating role. Talking informally with fellow colleagues they expressed a concern that although they would like to, they have not the time to work in this capacity, and had limited, if any, expertise in the field.

Table 2: Results of forum on role of psychologists working in special school environments

Principal (2)	Parent (1)	Psychologist (2)
* Referrals for: Challenging behaviour	* Advocacy	* Assessment
Assess situation/ programme/ additional resourcing	* Choice for placement assessment/allocation of resources	* Partnership
* Training for teacher teacher aide, special education assistant	* "Expert" acknowledgement	* Appropriate placement
* Provide hands on/ alongside teacher IEPs/goals/accessing	* Programming	* Counselling grief process
* Parental liaison		* Transition
* Cultural aspects		* Family dynamics
* Placement		* Co-ordinating role
* Counselling principals, parents, teachers		* Advocacy
		* Agreement with Ministry
		* Chalenging behaviour
		* Child development
		* Problem analysis

Although the key issues from the article from Presland (1989) and the information from the forum panel provided the much needed guidelines for working in this area, we did have additional problems.

The first of these was managing the workload within the special school setting. I chose to spend one day per week in every school, and spent Friday on report writing and additional reading and researching. On paper this seems an ideal situation, in that I gave each school considerable time each week, and had time to do the very valuable researching and reading. However, additional confounding variables made life difficult. Every school had spread most of their psychopaedic children throughout the whole school which meant that we were involved with practically all the staff. This diminished considerably the time available to each child and staff member.

This became increasingly difficult at one school where we had 26 children in 10 classes. Our team based at this school overcame this problem by targeting certain children per therapist according to their greatest need, so that those in most need of speech language therapist for feeding or communication

systems were the responsibility of the speech language therapist and, needless to say, I worked with the worst behavioural children.

In addition to this I contracted with the principal, and initially with the two other psychologists working at the school, to take staff meetings on assessment, IEPs, curriculum and observational techniques. These sessions were practically based and encouraged staff to work specifically on problems in their classes.

Another area of concern to the team was introduction of appropriate assessment and curriculum information. As discussed previously the children and young people in the Initiative presented in many cases with severe, profound, and multiple disabilities, and as such required specialist teaching and curriculum adaptation. However, because the schools had limited or no experience , and similarly limited information available to cope with the specialized needs of these young people they tried to accommodate these children with whatever was currently being used in the school. Consequently we were inundated initially with requests on this and I would like to acknowledge the valuable resource information given by my mentor Barry Carpenter, particularly on PMLD curriculum (1987, 1992) and assessment.

I had worked previously with similar young people using the Callier Asuza and the TARC assessments, but had since been working extensively with the Carolina (The Carolina Curriculum for Handicapped Infants and Infants at Risk, and Preschoolers with Special Needs) with children under Early Intervention. Some of the younger children in the Initiative had been on the Carolina prior to coming to school, and it seemed a natural progression to continue this into the school system also. However, because the older age group appeared to present with similar developmental levels as those covered by the Carolina (0-5 years), I was keen to introduce the use of the instrument with these folk also, and then adapt the programme to become age appropriate. Of particular benefit to them was the input into the sensory curriculum areas. I must stress however, that these assessments were only used as a guideline to providing appropriate goals, and not as a checklist through which each person must pass.

The procedure used to introduce the Carolina into the schools is worth noting. I initially assessed the young person with the teacher's assistance over, in some cases, three sessions. Many of the children were medically fragile and had 'off' days, and we also had those who presented with characteristic autistic tendencies, and therefore to get as near to an accurate picture we had to see each child over a number of sessions. I would then write up the assessment, discuss this with the teacher, and also where possible, the parent. The teacher then in collaboration with me assessed another child, and we discussed possible goals together. This procedure varied across schools. I spent longer with those teachers who were new to this area, and we assessed two or three children together before asking them to take responsibility.

A thorough assessment system which includes a staff enskillment component is time consuming and there is no easy way out as each one of these children present with an atypical pattern of development wih no apparent similarities. However, I did find the concept of problem analysis useful when trying to optimise the child's learning potential by analysing the child's strengths and channelling them into new learning situations. for example, we had one child who refused to track objects, yet could follow very closely the direction of her spoon when being fed!

Another common team problem area, which is not unique to the Initiative, was staff being slow to, or not adopting some of our suggestions. This was not always the case, we had some staff who could not get enough information! Possible reasons for this became apparent when I evaluated the year's work with the principals. We as specialists have , in some instances, an idealistic expectation or too optimistic view about the child's ability, whereas the teacher may have a clearer picture through working more closely with the child. There is also a time factor involved in that these young people do demand a high level of teacher input for normal daily routines such as feeding and toileting, and we pose additional requests for trips to the dark room, little room and swimming etc. It is therefore important for us to keep expectations at realistic levels, and to be appreciative of the teachers' role and time commitments.

On the whole we have seen considerable changes throughout the schools and it is exciting to be part of this. There are, however, as in any new field, emerging implications which need further investigation. Of particular concern is the transition issue. 50% of these young people will be leaving school within the next three years. It is crucial to ensure that their optimum development and quality of life continues.

Anne Gibbs, Manukau North Special Education Service, Auckland, New Zealand
Paper presented to the Special Education Service Conference at Dunedin, January 25-28, 1993

Speaker's Notes
from the
PMLD Conference held at
The University of Birmingham 1994

The Transition Years
Merillie Vaughan-Huxley
Copies of OHP transparencies

The FEFC has the duty to fund:

- sufficient educational places for all 16, 17 and 18 year olds who are not attending school;
- provision under Schedule 2 of the Further and Higher Education Act which includes a course preparing learners for entry to another course within Schedule 2 (as a progression towards a vocational qualification), for students aged 19 and over.

If the provisin you plan to offer falls within this definition an application should be made to FEFC under Schedule 2

Schedule 2

- a course which prepares to obtain a vocational qualification
- a course which prepares students to qualify for GCSE or GCSE A level
- a course which prepares students for entry to HE
- a course for basic literacy in English
- a course to improve the knowledge of English for those for whom English is a second language
- a course to teach the basic principals of mathematics
- a course for proficiency or literacy in Welsh
- a course to teach independent living and communication skills to persons having learning difficulties which prepares them for entry to another course

Funding

Funding can be a problem and will require planning and negotiation. Funding for provision for people with profound intellectual and multiple learning difficulties can be obtained from:

- the Further Education Funding Council
- the local education authority
- the social services department
- the health authorities
- any combination of these sources

The appropriate funder or funders will depend on what you wish to provide and for whom.

Why bother with transition?

- a student who is 19 years old but is at the developmental age of 6 months is not a baby
- the need to establish dignity
- the student is learning and should be in the learning system
- there is need for a philosophical view of why we are concerned with transition
- young people have the right to be treated as adults

Adult status/OECD

- full responsibility for one's own life and for decisions and choices
- being involved in productive activity, usually paid employment providing enough money to make on financially independent
- taking on adult roles in the community, including participation in leisure and recreation activities
- taking on adult roles in the family includng involvement in a variety of relationships
- a disability makes it difficult for them to achieve the level of competence generally regarded as necessary for adult status
- opportunities for learning which would enable them to develop greater competence are not available
- potential, or actual, competence is developed but their right to use it is not recognised by others
- students with profound and multiple learning difficulties may have no concept of transition
- we have to make the transition on their behalf
- parents, teachers, classroom assistants have a role
- few students with PMLD the number is growing
- good quality provision depends on teachers having advanced qualifications so that young people do not simply perform task but learning can be structured.

PROMOTING QUALITY OF LIFE FOR PEOPLE WITH PMLD: THE SCHOOL YEARS

Judy Sebba, University of Cambridge, Institute of Education.

Introduction

This brief presentation attempts to address 3 aspects of the quality of life for pupils with PMLD during the school years:

- equality of opportunity
- entitlement, access and achievement
- monitoring and evaluation

The focus will be on within school aspects while recognising the important role of activities and lifestyle outside school. The coverage will necessarily be superficial and inevitably focuses on the specific areas in which I have been most involved over the past 3 years - curricular issues and quality of teaching and learning.

A brief historical perspective may encourage recognition of progress made in provision over the past 25 years although it is intended to stimulate further progress rather than lead to complacency.

In 1971, I worked in a special care unit of a school for pupils with SLD. Twelve pupils with PMLD (characterised by immobility and lack of speech in all but one child - the active, self injurious population inhabited the classroom opposite) were 'taught' by one teacher and two welfare assistants. Most of the pupils had wheelchairs or buggies and we had tables with 'cut-outs' and some variety in seating as well as wedges. We did not have standing frames, prone boards, Snoezelen, light/dark rooms, computers, switches or a swimming/hydrotherapy pool.

The curriculum was characterised by tasting, smelling, painting, music and Sherborne movement. There was lots of physiotherapy and most of the day was spent toileting. The classroom environment was seen as stimulating - radio or music blaring and items hanging from the ceiling. A few pupils had glasses, none hearing aids. Record keeping was confined to fits, bowels and feeding and there was no contact with the rest of the school. There were no staff development opportunities, although most teachers had transferred from health and were therefore required to go and train or reconsider their employment.

How does quality of life differ today for these pupils?

Equality of opportunity

Pupils with PMLD are often distributed throughout the classes of schools for pupils with SLD. Where they are not, they will typically experience better staffing ratios than occurred in 1971, or than occurs in many other parts of the world today. Segregation of pupils with PMLD has the obvious disadvantages of lack of social interaction and appropriate role models, potential narrowing of the curriculum and teachers throughout the school not taking responsibility for the full range of needs. However, systematic evaluations are lacking and as O'Connell (1994) noted, other pupils (with SLD or in mainstream) will need some disability awareness if they are expected to do more than treat pupils with PMLD as helpless babies. Distributing pupils with PMLD throughout the school will not bring about equality of opportunity unless supported by staff development, careful planning and creative organisation. However, given the increasing proportion of these pupils in the school, segregation will rapidly become non viable.

Entitlement, Access and Achievement

There has been much discussion about whether the introduction of the National Curriculum (NC) has moved beyond legal entitlement to increasing access and

achievement for pupils with PMLD or has merely distracted us from the real priorities for these pupils. Ware (1994) suggests that the NC stimulated discussion of curricular issues beyond the well-established daily living skills. She notes the tension between the NC within which the aims of education are the same for all children and whether the priorities for these pupils can best be met by the NC.

However, a point we have repeatedly reiterated (Sebba & Byers, 1992; Sebba et al, 1993; Rose et al, 1994) is that the NC is not intended to constitute the whole curriculum. This is now stated clearly in the final Dearing report on the review of the NC (Dearing, 1994) and is reflected in the revision of the criteria for school inspections (OFSTED, 1994) which refers to standards as:

> What pupils know, understand and can do... in the subjects of **their curriculum, including** NC subjects....

and

> Pupils' competence in the key skills.... in the curriculum **as a whole**.

Within the whole curriculum there is still greater scope for integrating NC and the developmental or additional curricular activities. In Sebba et al (1993) Byers describes how a pupil's individual priority of arm stretching can be targeted within a variety of activities, some of which are based on NC programmes of study. Ware (1994) provides clear examples of this process including an activity with food in which some pupils may be addressing targets in Science or History while pupils with PMLD are taught chewing, finger feeding, anticipation and discrimination tasks. Activities from the developmental or additional curriculum may not sit comfortably within the NC but must be justified through clear objectives and evaluated with the same rigour.

For this process to be effective, it is essential for the recording to distinguish clearly between experience or curricular coverage and achievement. Often, the pupil with PMLD will be experiencing an activity derived from the NC programmes of study but achieving a priority that may not relate to the NC. Rose (1994) provides an example of an accreditation system at Wren Spinney School which enables this distinction to be clearly made.

The reasons for extending these wider experiences to pupils with PMLD are many. It enables individual priorities to be addressed in an appropriate context, opportunities for progression are more likely to be available (particularly important for pupils whose physical and sensory difficulties may be masking cognitive skills) and pupils are subjected to the benefits of paired or group work (see Sebba et al, 1993 for further discussion of this).

Concerns about the NC have been partly addressed by the Dearing review - access statements about using augmentative communication will appear consistently in all revised Orders and an attempt has been made to create access to **all** levels at all key stages (although it is not always possible to do so in practice). Most importantly, there is now flexibility through the 'enabling' clause to work on the key stage programmes of study that, in the teachers' judgement, will enable individual pupils to **progress and demonstrate achievement.** The greater emphasis on programmes of study as a basis for planning, teaching and assessment will also be helpful in increasing access.

However, the problems have by no means be resolved. Pupils with PMLD are by no means well served by the NC, in particular by formal assessment arrangements. The NFER small steps study will help address the issue of what constitutes 'effective practice' in reporting achievement for pupils whose progress is not reflected in the level descriptions. The issue of how formal assessment is tackled more creatively than

resorting to 'w' is yet to be resolved. However, it is encouraging to see that PMLD issues are receiving proper recognition.

Developments in teaching approaches

Concern with curricular content may have distracted us from the debate about teaching approaches. However, there is widespread acceptance of the need to move away from exclusively teacher-directed, task-analysed, behavioural objectives taught individually towards more balanced and varied teaching styles. Creating meaningful environments which support development of communication through the use of real objects, symbols and staff who encourage intentional communication are usefully described in Goldbart (1994) and Fergusson (1994). The use of 'sabotage' techniques to encourage communication as suggested by Kiernan et al (1987) has been further developed by Byers (1994) who describes the approach of the 'crazy teacher' who encouraged pupils to react to fish that jumped, rabbits that flew and shoes that appeared to have taken root in the garden. The pupils' laughter was welcomed as an indicator of 'engagement' whether or not the incongruity of concepts had been fully grasped.

The work of Nind and Hewett (1994) has made a significant contribution to discussion of teaching methodology with people with PMLD. While the people with whom they worked were all post school age, their techniques of intensive interaction derived from the social-psychological literature are being adopted in schools. The approach is based on the importance of establishing interactive relationships through pupil-directed activities in context aimed at developing reciprocity. The physical contact and vocal behaviour involved raises challenging issues, particularly in relation to the 'age appropriateness' debate. Fletcher and Gordon (1994) provide a helpful conceptualisation of this issue:

> The notion of autonomy and adult status for students with PMLD requires an interpretation of the curriculum which avoids tokenism yet which is consistent with the aim of empowerment in as many aspects of their lives as possible. Learners who may not achieve the main indicators of adulthood, nevertheless have the right to the dignity and status accorded to others of a similar age (p.30).

Monitoring and Evaluation

Do teachers working with pupils with PMLD require specific skills? Undoubtedly there are technical aspects of handling, lifting, use of equipment, medical management and early communication work for which training will be needed. The basic teaching skills would appear similar. Looking at the OFSTED (1994) criteria for quality of teaching (see attached) there is little to disagree with in any classroom.

Interpretation of these criteria in a PMLD context is a different matter. The reluctance of inspectors to bid for inspections this term in schools for SLD and EBD may be related to concerns about the difficulties of making these judgements (particularly in relation to quality of learning and standards since no real national picture is available). Use will need to be made of additional information from records, reports, annual reviews, RoAs, etc.

Schools can take the opportunity to use the criteria for formal monitoring and evaluation through inspections as a basis for self review. It will be important to monitor and evaluate individual priorities and broader curricular coverage. The establishment of internal mechanisms for monitoring and evaluation will provide a sound basis for identifying issues for further development.

The Code of Practice (DfE. 1994) offers additional structure to the assessment, recording and reporting process which will provide information for schools to

monitor and evaluate. The Code challenges us to involve pupils and parents to an even greater extent than we have done in the past. How might pupils with PMLD be meaningfully involved in this process? This offers an important challenge for the future.

Conclusion

The quality of life for pupils with PMLD has certainly been enriched. The curriculum is broader, there is contact with a wider range of other pupils and staff and teaching approaches have diversified. Throughout this process there has been an appropriate concern to maintain a strong emphasis on their individual priorities.

The changes in national policies that have included all pupils have led to an important process taking place. Politicians, quango chief executives and mainstream inspectors are discussing issues relating to the needs of PMLD pupils. This constitutes real progress in a society in which policy makers previously would have remained blissfully unaware of their existence.

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STANDARDS OF ACHIEVEMENT

What pupils know, understand and can do in the areas of learning pre-Key Stage 1; in the subjects of their curriculum, including the ATs and PoS of NC subjects and agreed syllabuses for RE; in the examination or accreditation requirements of other courses pre- and post-16.

Pupils' competence in the key skills within reading, writing, speaking and listening, number and IT, in the curriculum as a whole.

Inspectors should compare the results of Key Stage assessments, public exams and other accreditation with national averages (where available) and assess the achievements of pupils in relation to those expected of average pupils of a given age.

Inspectors should assess separately whether these standards are appropriate to the pupils' abilities and previous attainment.

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(In a school with high standards, the great majority of pupils show high achievement in most areas of work.

Where standards are satisfactory or better, pupils achieve standards which are at least commensurate with what is known of their potential. Those of average ability attain standards that compare well with national norms; those of below average ability achieve creditable standards; and those of above average attain high standards that reflect their potential. There is little variation in the standards achieved in different subject areas and activities.)

QUALITY OF LEARNING

The **progress** made in knowledge, understanding and skills, including reading, writing, speaking and listening, number work and IT;

learning skills including:-

- observation and information seeking;
- looking for patterns and deeper understanding;
- communicating information and ideas in various ways;
- posing questions and solving problems;
- applying what has been learned to unfamiliar situations;
- evaluating work done.

attitudes to learning, including:-

- motivation;
- interest;
- the ability to concentrate;
- the ability to cooperate;
- the ability to work productively.

****

(Where learning is good, most pupils respond readily to the challenge of the tasks set, show a willingness to concentrate on them, and make good progress. They adjust well to the demands of working in different contexts, selecting appropriate methods and organising effectively the resources they need. Work is sustained with a sense of commitment and enjoyment. Pupils are sufficiently confident and alert to raise questions and to persevere with their work when answers are not readily available. They evaluate their own work and come to realistic judgements about it. Where appropriate, pupils readily help one another.)

QUALITY OF TEACHING

The extent to which:

- teachers have **clear objectives** for their lessons;
- **pupils are aware** of these objectives;
- teachers have a **secure command** of the subject:
- lessons have **suitable content**;
- activities are **well chosen** to promote learning of that content;
- activities are presented in ways which will **engage and motivate and challenge all pupils**, enabling them to make **progress** at **a suitable pace** and to be aware of their achievements and progress

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(Where teaching is good pupils acquire knowledge, skills and understanding progressively. The lessons have clear aims and purposes. They cater appropriately for the learning of pupils with differing abilities and interests, and ensure the full participation of all. The teaching methods suit the topic or subject as well as the pupils; the conduct of the lesson signals high expectations of all pupils and sets high but attainable challenges. There is regular feedback which helps pupils to make progress, both through thoughtful marking and discussion of work with pupils. Relationships are positive and promote pupils' motivation. National Curriculum ATs and PoS are taken fully into account. Where appropriate homework which extends or complements the work done in lessons is set regularly.)

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FUTURE FOCUS
Early Years

Some readers will have obtained through SCAA their draft proposals for Pre-School Education, 'Desirable Outcomes for Children's Learning' (September 1995). The Early Years phase of education often presents greater curriculum compatibility for pupils with PMLD than any other phase of education. So naturally interest and curiosity (good early childhood traits) were high as I delved into this latest SCAA missive.

Frustration and disappointment were the outcomes of my reading of this document (not at all desirable!). The lone reference to special needs appears in the Introduction.

> *Some children, particularly those with identified special educational needs, will require sustained support for achieving all or some of the outcomes after entering compulsory schooling.* (p. 7)

Read that sentence again! For many children with PMLD that means that their whole school career could remain rooted in a document outlining pre-school education. When you consider the headings the 'desirable outcomes' are listed under, then you begin to realise that the previous sentence holds some truth – 'Personal and Social Development', 'Language and Literacy', 'Mathematics', 'Knowledge and Understanding of the World', 'Physical Development and Creativity'.

So much innovation has taken place in adapting the Early Years Curriculum to ensure that it embraces our youngest children with SEN, including those with PMLD. If sensory approaches to the curriculum have an obvious place, then it is supporting early learning experiences for children with PMLD. Adaptation of the High/Scope Curriculum (Mitchell, 1994) have similarly presented elements of choice into the learning plans of all children with special educational needs. The design of the SCAA document would militate against any notions of charting progress for children with PMLD, and, as Ware (1994) has pointed out, this remains the major challenge of teachers working in this field.

The Early Years should be a time of awe and wonder in every child's life, regardless of the severity and profundity of their disability. Free of the constraints of the Curriculum structures which arrive with statutory schooling, teachers can do much to establish interactive patterns of learning with the young child with PMLD. Innovation and experimentation should be features of good practice in early childhood education, but these do not appear in the SCAA 'Significant Features of Good Practice' (p. 13).

Services for children under five in the UK are variously redescribed as a 'national disgrace' (Ball, 1994) or as offering parents a rich range and diversity from which to choose (Secretary of State for Education, 1994). Advocates of quality early childhood education, such as Gillian Pugh are still having to make statements such as this:

> *It seems shameful that at the end of the twentieth century, after countless reports from researchers and national committees, we are still having to make the case that a child's early years are of critical and lasting importance.* (Pugh, 1994)

This is true for *all* children. Hence we need to be part of the national debate about Early Years provision and education. For the crisis is even greater for young children with PMLD and their families. We have seen a gradual erosion of Early Intervention services in this country. With each round of education budget cuts, non-statutory aspects of provision, such as pre-school teams, are cut. Special educators, in whatever setting they may work, appear to have lost their capacity to articulate the general need for Early Intervention services for our children and their families (Carpenter, 1994). What will 'vouchers' do for nursery provision for pupils with PMLD?

The victims of poor early childhood provision are the children themselves. If very young children with PMLD fail to receive support and intervention from a variety of professionals during their vital Early Years, then their capacity of engage in the learning process is severely diminished. It is the fundamental right of all children to be dignified by their learning. The foundations are the Early Years, and the challenge that faces us is how do we offer quality early education experience to our youngest children with PMLD?

The Editorial Team of *PMLD Link* would welcome your views and particularly examples of your practice.

Barry Carpenter
CSSE, Westminster College, Oxford

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Chris Stevens, Professional Officer (SEN) at SCAA will be leaving next February to take up a new post at the National Council for Educational Technology. Chris has done much to ensure that special educational needs remained high on the agenda at SCAA, and previously at NCC. He was primarily responsible for the latest SCAA SEN initiative, 'Planning the whole Curriculum for Pupils with PMLD', which will be published later this year. This document reflects Chris's balanced approach to meeting the needs of children with PMLD, and, like Chris himself, is realistic and down-to-earth.

We are grateful to Chris fro his hard work at SCAA as an advocate for teachers and children in Special Education. We wish him well in his new post.

Barry Carpenter
on behalf of the Editorial Group of *PMLD-Link*

Play it my way: learning through play with your visually impaired child

Royal National Institute for the Blind
HMSO, 1995,139 pp
Paperback £9.95
ISBN 0-11-701676-4

Although the subtitle of this book is "learning through play with your visually impaired child" it also considers the needs of multi-disabled children. It is primarily written for parents and carers, but nevertheless it is highly relevant to all who work with or care for young children with profound and multiple learning disabilities. It is intended to be a resource book to dip into, and a springboard for those parents who have difficulty in getting started with a child who is slow to respond, whatever the cause of this may be.

It is written in straightforward language, avoiding the use of jargon but still giving a wealth of information about the implications of disability for play and development, and many practical suggestions to help to overcome or compensate for this. Clear and attractive drawings illustrate some of the suggestions, and further increase the book's 'reader friendliness'.

Each of the six chapters focuses upon a particular aspect of development and learning which can be encouraged through play activities. Information is given of how sighted children respond and develop and the implications for a child with visual impairment or multiple disability are explained.

The main part of each chapter is devoted to 'partnership activities' in which simple and practical suggestions are made for playing with and encouraging a child to start to play, and moving from assisted to independent play. As well as describing activities and giving ideas for toys to make or buy, there are hints on helpful techniques to use, such as backward chaining, the use of physical guidance and prompts, the use of language. Throughout the book, the message recurs that we must use encouragement, praise, persistence, patience and time to make the most of the opportunities that exist for play.

The two chapters which focus on self help and personal care (eating and drinking, and washing, toilet training, sleeping and dressing) are full of hints, and provide a practical account of strategies to use to encourage independence in these areas. The first provides a very useful analysis of the skills needed for learning to eat as well as dealing with the emotional aspect of eating and enjoying food. The second of these two chapters, in addition to addressing the other self care skill, deals with a range of common problems such as head banging, screaming, over activity, remoteness, resistance to being handled, resistance to handling objects; and suggestions are made for activities to try in each case.

The final chapter, 'Everyday Life', emphasises the importance of play for all children and discusses the many forms of play. In the section on 'partnership activities' it shows how to make the most of everyday situations, and encourage the child to use these experiences in imaginative, creative and imitative play. Two webs (a format familiar to teachers, but perhaps a new way of looking at things for parents and carers) are used to give a clear overview of how everyday situations can be used to develop awareness and understanding, provide opportunities for learning, and to show the interconnections between all the areas of learning.

Three appendices give further suggestions for reading, information on services for children, and a list of national organisations.

Although no book can be a comprehensive guide to play opportunities in every situation, there were instances when opportunities to show the possibilities for play were lost, particularly those described in the chapters dealing with self help and personal care which were rather more instructional in tone. Nevertheless, this book fulfils its stated aim to act as a resource, and provide a helpful starting point to generate ideas for enjoyment, learning and having fun together. The wealth of information about all aspects of development and the many practical ideas for play that it contains, will provide a most useful resource for parents and professionals who are involved with children with multiple disabilities.

Carol Ouvry is editor of *PMLD Link*.

Augmentative Communication in Practice: an introduction.

Millar, S. and Wilson, A.

CALL Centre, University of Edinburgh, 1994, 66 pp
Paperback £5.00.
ISBN 1-898042-03-9

This book provides a good overview, at a general level, of what constitutes alternative and augmentative communication. It is easy to read and its format, which includes pictures and boxed, highlighted quotations, is visually very acceptable.

As a source of information at an introductory level, this book indeed achieves its stated aim. The first chapter, by Sally Millar, deals with a definition of augmentative and alternative communication (AAC). She gives (on page 8) a definition of who constitutes the AAC team. It is sad to see that the user is not included as part of that team. Many other writers in this field at the moment are stressing the need for the user's viewpoint to be taken into consideration. Indeed, later in this book, in a pertinent and succinct chapter by Janet Scott, there is a quote from Rikki Creech, an AAC user, which argues that "the communication aid is just the key that unlocks the door to the candy shop. I am the candy." At times this book fails to maintain the centrality of the AAC user in the practice that it advocates.

The chapter by Alison MacDonald on symbol systems gives a very thorough, but brief, overview of the development of a variety of symbol systems, not only in the UK, but also in North America and Australia. The diagrams she uses for comparative purposes would be very helpful to anyone considering which AAC system to use.

The book gives a technical perspective on AAC rather than an educational one. In many of the case studies given, the authors talk about beginning AAC programmes with much older children. Obviously there are significant benefits if, in the early years, an intervention programme based on AAC can be initiated for a child. Other research of late has been showing that children who have been exposed to AAC very early have been significantly helped in their later speech development. The use of AAC may help children with perceptual or cognitive disabilities to develop their skills in expressive and receptive language more extensively.

The use of any AAC system does not just concern teaching the learner about the use of symbols. Rather it is about the functional and interactive application of what, in effect, becomes their communication system. The variety of contexts and significant others with whom the AAC user will interact also needs to be given due consideration.

At a foundation level, this book certainly gives some useful insights and there are many useful addresses and signposts to further references that can be obtained from this book. However, for anyone seriously considering using AAC, then the book would need to be used in conjunction with literature that discusses some of the wider implications of AAC systems.

Margarida Nunes da Ponte, from Lisbon, Portugal, is currently undertaking research in augmentative communication at the Centre for the Study of Special Education, Westminster College, Oxford.

Taking Control: enabling people with learning difficulties.

Coupe O'Kane, J. and Smith, B. (eds).

Fulton, 1994, 178 pp
Paperback £16.99.
ISBN 1-85346-230-6

Juliet Goldbart's crisp and incisive overview of the contents of this book leave the reader thirsting to drink of them. She generates a mood of enthusiasm which encourages all readers, of whatever background, vigorously to plot their own route, according to their particular needs, through the pages of this edited volume.

To empower people with learning difficulties to take control of their lives, we have to consider the extent to which society imposes controls. Beryl Smith does this with the debate she raises in the opening chapter about dependency and 'learned helplessness'. In so doing she asks the questions which are central to this book. How do we hand over control? How do we enable people with learning difficulties to participate actively in the process of empowerment? This theme is continued in

chapter 2 by Coupe O'Kane, Porter and Taylor, but from a different ideological standpoint. These authors contribute a valuable debate on cross-curricular themes, skills and dimensions.

John Harris considers how the personal power of the individual with learning difficulties hinges on their capacity to communicate effectively. He gives a detailed analysis of communicative acts but at no point in this discourse have the needs of people whose communication rests on alternative and augmentative approaches been mentioned.

The chapter on contingency awareness relating to those with profound and multiple learning difficulties I found difficult because I was unsure what new insights a chapter could offer when the most recent reference was 1986 and the majority of the supporting literature over a decade old. In contrast, the chapter by Chris Wilkinson was instantly captivating, relating theory to practice. Williamson provides a very useful list of points for checking the meaningfulness and relevance of the environment for students with profound and multiple learning difficulties.

As Suzie Mitchell states in her clearly written, unambiguous chapter, the High/Scope curriculum offers a challenge to some teachers to restructure parts of their practice to enable children to take control by initiating some of their own learning experiences. She demonstrates, as does Richard Byers in the subsequent chapter, how behavioural and cognitive approaches can coexist.

Byers articulates the experiences of many teachers in SLD/MLD education over the last two decades. As ever with this author, his focus on the whole child in the context of the whole curriculum is refreshing and enables teachers to feel safe in the knowledge that they can select the teaching strategy which will meet the individual needs of their children.

Steve Parker recalls the value of the Technical and Vocational Education Initiative (TVEI) and the impact on curriculum development for students with special educational needs. A tangential development from TVEI has been Records of Achievement. There seems to be almost universal acceptance by teachers in all schools of their value and, in the field of learning difficulties, the need for student self-assessment has led to some innovative practice, as Parker illustrates.

Keith Winrup gives a very practical account of the role of a student committee and how this can be an empowering strategy, particularly for students with learning difficulties in post-16 education. Decision-making and self-advocacy are inherent in this process, with implicit value for the students.

One of the strengths of this volume is that it reinforces the notion of life-long learning as a self-empowering strategy for people with learning difficulties. Thus the chapter by John and Speake, dealing with personal effectiveness of adults in the community, is particularly welcome.

Roy McConkey advocates the 'ordinary life' philosophy in which adults with learning difficulties are entitled to a home, employment, leisure and specialist services in their community. His challenge to us is: "Do we believe that special people can live ordinary lives?" If we do, McConkey offers thought provoking material on how we might serve these individuals.

This book concludes with two sensitive contributions, the first from Mary and Christopher Lodge and the second from Angela Jones, who powerfully remind us that whatever intervention support strategies we choose we must consider the impact on the family. As a parent of a child with learning difficulties, I found great reassurance in the messages offered by this concluding chapter.

In spite of one or two pitfalls, this book nobly achieves its goal and builds a valuable bridge between the child-based education literature and the adult-based service-provider literature. This is yet another text from the Fulton publishing house which is promoting quality of life through effective education for people with learning difficulties.

Barry Carpenter is Director, Centre for the Study of Special Education, Westminster College, Oxford.

BOOKS

Religious Education for All by Erica Brown, publication by David Fulton Publishers expected January 1996 ISBN 1-85346-392-2

Early Intervention: 'Where are we now?' edited by Barry Carpenter published by Westminster College 1994. Available from Westminster College, Oxford 01865-7-247644. ISBN 1898003-0-

Planning the Curriculum for Pupils with Special Educational Needs: A Practical Guide by Richard Byers and Richard Rose published by David Fulton 1995 ISBN 1-85346-387-6

Social Skills for People with Learning Disabilities: A social capability approach by Mark Burton, Carolyn Kagan with Pat Clements published by Chapman and Hall Ltd 1995 ISBN 0-412-43380-X

The Practical Guide to Multisensory Rooms by Mark Gray and Richard Hirstwood published by TFH Publishing 1995

Movement, Gesture and Sign published by RNIB 1995

The Massage and Aromatherapy Workbook by Avril McConnell 1995 available from Jade College of Natural Therapy 12 Jenkyn Road, Wootton, Bedford, MD43 9HE

Planning the Curriculum for pupils with profound and multiple learning difficulties published by SCAA expected early 1996

RESOURCES

Video

Massage Vol. 1 - a practical introductin to massage, demonstrated by Avril McConnell. The video works in conjunction with the 'Massage and Aromatherapy Workbook'. In addition to the necessary basic skills of massage movements the video demonstrates two complete massage routines Hand and Arm Massage, Leg and Foot Massage. Agailable from Jade College of Natural Therapy, 12 Jenkyn Road, Wootton, Bedford MK43 9HE

Packs

VITAL information for people working with visually impaired children who have additional special needs compiled by VITAL-the RNIB/VIEW curriculum group for multi disabled visually impaired children. Available from RNIB Education Information Service, 224 Great Portland Street, London W1N 6AA

Equipment

Vibropulse Therapy the use of vibrotactile stimuli in education using the vibropulse unit. Training course developed by Dr. David Byrne in association with Vibro-Medico. Information from Vibro-Medico 20, Church Road, Hadleigh, Essex SS7 2DQ

TRAINING

Training Packs

Rights and Entitlements: understanding benefits and allowances. for people who have profound and multiple disabilities. A workshop training package in support of parents and carers by Paul Burgess and Helen Mount. £45.00 (inc. p&p) Available from Mencap PMD Section, Piper Hill School, 200 Yew Tree Lane, Northenden, Manchester M23 0FF

Long Courses

Professional Development Diploma in Therapeutic Horticulture
Horticultural Therapy in conjunction with Coventry University
3 Module, 30 week course on day release basis. open to those with degree or diploma in Occupational Therapy or Horticulture.
Applications to: Admissions and Placement Unit, Schol of Health and Social Sciences, Room A116, Coventry University, Priory Street, Coventry CV1 5FB Tel: 01203 838634

Training: Courses/Conferences 1996

JANUARY

26th — Drama for people with PMLD
Exploring and experimenting with games, exercises and drama activities
Discussion of practical and theoretical considerations.
Led by Andy Battell
Run by PLAYTRAC
Venue: Playtrac Training Suite, Harperbery, Herts
Further details: Playtrac Training Consultants
Tel: 01923 854861

FEBRUARY

2nd — Relaxation
Using relaxation, simple massage and body awareness exercises with people with learning disabilities
Led by: Andy Battell
Run by: PLAYTRAC
Venue: Playtrac Training Suite, Harperbery, Herts
Further details: Playtrac Training Consultants
Tel: 01923 854861

2nd — IT, Disability and Lifelong Learning
A conference to explore the ways in which IT can enable education and employment for all and to look at the relevance of virtual reality and multimedia to SEN and the role of electronic communications in' supporting SEN co-ordinators
Run by NCET
Venue: Church HouseConference Centre, Westminster, London
Further details: Tracey Baldwin, NCET
Tel: 01203 416994

6th and 7th — Recognising, assessing & managing issues of sexual abuse for people with learning diffiuclties
Run by: Horizon NHS Trust Sex Education Team
Further details: Sex Eudcation Team, Harperbury Hospital
Tel: 01923 854861 X 4420

7th — Profound and Multiple Learning Difficulties
"Issues of Communication"
Keynote presentation followed by seminars/workshops
Organised by: MENCAP PIMD Section
Venue: Didsbury School of Education
Further details: Hilda Bolton, Manchester Metropolitan University
Tel: 0161-247-6425

12th and 13th — Essential Lifestyle Planning
Course for people who wnat to learn how to facilitate Essential Lifestyle Planning.
Run by: Manchester Joint Service for People with Learning Disability
Venue: Manchester
Further details: Helen Sanderson
Tel: 0161-223-9901

15th and 16th — Essential Lifestyle Planning
Repeat of above course. .

MARCH

7th and 14th — Dance Dynamics
Day one: creative dance and movement shared with a partner with learning disability on day two.
Run by: PLAYTRAC
Led by Wolfgang Stange
Venue: Playtrac Training Suite, Harperbery, Herts
Furtrher details: Playtrac Training Consultants
Tel: 01923-854861

12th — Cultural Diversity and Learning Disability
Conference aimed at raising awareness and sharing knowledge about the multi-cultural needs of people with learning disailities. Examples of good practice, opportunity for debate and networking.
Organised by: Ravenswood
Venue: Kings Fund Centre, London
Further details; Shirlee Sharpe
Tel: 0181-954-4555

28th — Moving into the Community
Issues of transition from long stay institutions into community settings for people with learning disabilities.
Run by: PLAYTRAC
Led by: Noelle Blackman and Irma Mullins
Venue: Playtrac Training Suite, Harperbury, Herts
Further details: PLaytrac Training Consultants
Tel: 01923-854861

APRIL

2nd and 3rd — Recognising, asessing & managing issues of sexual abuse for people with learning diffiuclties
Run by: Horizon NHS Trust Sex Education Team
Further details: Sex Education Team, Harperbury Hospital
Tel: 01923-854861 X 4420

30th — Cultural issues in sexuality work with people with learning difficulties
Run by: Horizon NHS Trust Sex Education Team
Further details: as above

MAY

7th and 8th — Sexukality and sexual health issues for women with profound learning difficulties
Run by: Horizon NHS Trust, Harperbury Hospital
Further details: as above

AUGUST

30th to 1st Sept — World Congress on Rett Syndrome
"Hand in Hand with Rett Syndrome"
Gothenburg, Sweden
Further details: Congress President, Anita W-Ljungberg, Box 259, S-791 26 Falun, Sweden

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