

PMLD**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

Most of the articles in this issue are on the theme of overcoming barriers to inclusion, but vary widely in their perspective. They cover the Disability Discrimination Act and its implications for services; research into inclusion in schools in this country and Canada; they look at ethical and practical issues involved in facilitating inclusion; describe inclusion projects in schools and also first steps to inclusion in Guiding; and discuss the difficulties facing disabled children when services don't work as well as they could or should. The themed articles culminate in a celebration of good practice written by pupils of Cleves school in Newham. The ethos of the school in valuing everyone equally is expressed by all the writers – each in his or her own way.

An article on Pica is of specific interest, particularly to those carers and practitioners who have had experience of the problem. Hopefully it will open up discussion, and prompt other people to pool their experiences, either by writing to PMLD-Link or contacting Dionne Dsa, the writer of the article.

This year BILD (the British Institute of Learning Disability) is running two special items/events focusing on profound and multiple disability. The October issue of the Learning Disability Bulletin will gather together reprints of relevant recent articles, and the theme of their Conference in November is 'Valuing good practice for children and young people with severe and profound and multiple learning difficulties.' It is good to have this focus from a national organization such as BILD.

Also of interest to some readers will be the recent issue of Eye Contact with the theme of technology for children with visual disability. Many of these articles are relevant for people working with people with profound and multiple disabilities.

Business matters

Our next issue is also on technology – high and low. Do write in with any information or comments on resources you find particularly useful. But articles on any subject at all are welcomed.

Articles for the next issue should reach me by the beginning of November. Send them by e-mail or by post, but do be sure to include the name of the writer(s) and contact details in case any reader would like to respond. Also, please send your full address so that I can send a copy of PMLD-Link to every contributor. Not all are subscribers and it can sometimes take quite a lot of detective work to ensure that every writer gets a copy!

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

FUTURE FOCUS - Using Technology

The next issue is on the use of technology, and this begs the question 'What do we mean by technology?' When I was a class teacher in a school for Severe Learning Difficulties at the time when the government was funding computers for schools, it would definitely have meant a computer or, possibly, some kind of communication aid which made use of computer technology. At the time a great deal of innovative work was done to develop programs and control devices to enable pupils with profound learning disability and /or multiple disabilities to use the machines. Since then technology has been applied to a very wide range of toys, equipment and aids for daily living and learning, and the process of making decisions about what to purchase can be fraught with difficulty. There are many expensive items of equipment languishing in cupboards or drawers for one reason or another.

Multisensory rooms are prime examples of 'high tech' and Pagliano (1999) in his book entitled *Multisensory Environments* reminds us of the range of equipment used in specialized conditions (which include dark, sound and light rooms for example). Such environments offer opportunities for relaxation, stimulation of the senses, decision making, interaction and the development of communication, and the facilitation of therapy. Do the specialized environments in your setting offer these or other opportunities? Why not tell us about your pupil's experiences and achievements and how they are evaluated?

However, there is a counterpart to 'high tech' aids and equipment which has been referred to as 'low tech' (Ouvry and Mitchell 1995) by which is meant those particular aids and devices which have been developed with a particular individual's needs in mind to fulfil a particular purpose for that person, but which are not dependent upon computer technology. These items of equipment are often made by a carer or practitioner to enhance the learning or lifestyle of a person with whom they work. A number of well-known names spring to mind as proponents of this 'low tech' approach: Flo Longhorn, Phoebe Caldwell, and Chris Fuller of Bag Books among many others. A number of organizations such as Action for Leisure and Information Exchange have promoted them in bulletins and publications. These devices can combine the needs of the individual with his or her particular preferences and interests, and at the same time take account of the person's age and personality, thereby protecting their dignity while catering for their interests. One of the greatest advantages is their relative cheapness compared to 'high tech' devices.

It can be tempting to go for the 'high tech' solution without considering whether there is a more modest answer to a problem particularly as, in my experience, it is so much easier to fund-raise for something expensive and spectacular than for something more prosaic but possibly more practical. How do you choose? What criteria should be considered when making these decisions? Are there issues which should always be taken into account when deciding?

In the next issue of PMLD-Link we would like readers to let us know of any high or low tech equipment that you or one of your pupils, clients, or family members have found particularly useful, interesting, fun or helpful in teaching and learning. Let us know how it is used, where it came from, how you decided to use it, or whether you would have used something different with hindsight. Pass on your ideas and experiences to others whether you work in the community, in schools, with young people or adults, or in the home – everyone's experiences are of value. Do let us have your views – write in!

**Carol Ouvry
Christina Tilstone**

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REAL INCLUSION FOR CHILDREN WITH PMLD

A Segregated Life

A child experiencing profound and multiple learning difficulties typically goes to a special (segregated) school, possibly a specialist (segregated) college and then stays at home or goes to a special (segregated) centre. Their links with mainstream society are very tenuous. They are regarded negatively, simply as people with severe impairments, rather than as individuals with personalities. Their schools, colleges and centres may be warm, friendly places, but they are not part of the community.

Inclusion in Mainstream School

When people have talked about inclusion for this group, they have often meant inclusion within the special school. Since 1993, Cleves School, in the London borough of Newham, has been an isolated example of fully including these children in a mainstream school. In other areas, where inclusion has been developing, it has not extended to this group of children. Recent legislation, especially Part 4 of the Disability Discrimination Act (DDA), means that inclusion must now be looked on as an option for all children.

Full Inclusion in 5 Bolton Mainstream Primary Schools

Because of the DDA, all parents should be able to choose to have their child included in their local school of choice. When a child has very complex needs, it may be difficult to meet the child's needs in their local school. That is why, in Bolton, we have developed 5 mainstream schools in different areas of the town that are fully inclusive. This means that they are resourced to take children with severe, profound and multiple learning difficulties. The criteria for entry to the resourced provision in these schools is just the same as for the local special school.

Children will come into the schools in the nursery or reception class and then go through the school with their typically developing peers, not in a unit but fully included in all activities. No child is too impaired. All parents have the choice to send their child to one of these schools as an alternative to a special school and will be positively encouraged to do so.

The schools are in new buildings with larger classrooms and big resource areas. They have therapy rooms, including a multi-sensory room, and disabled toilets and changing facilities. Most importantly, the staff are being trained so that they can feel confident to adapt the curriculum to fully include these children. The headteachers have visited Cleves Primary school in Newham. Visits are ongoing to other resourced schools and to the local special school. The staff will have support from therapists and from an advisory teacher with experience of teaching children with severe and profound impairments. They will have special needs assistants, who will have ongoing training to meet their needs.

The Magic Ingredient

However, the most important part of the inclusion process, especially for children experiencing profound and multiple impairments, is the other mainstream children in their class. The children will grow up with their peer group. There is a great deal of anecdotal evidence to show that children respond to disabled children, not just with affection, but with lots of ideas to adapt the curriculum. They become communicative partners, intensive interactors and friends. They provide, in a natural way, the stimulating environment that the children need. Who better than classroom friends to theme a multi-sensory room and then to share the enjoyment of it?

A Pilot Scheme

Before any of the buildings were ready, or any children had started at the schools, two children with profound and multiple impairments at a social services daycare unit visited the nursery class or a local primary school each week. These visits were clearly beneficial to both groups of children. Here is just one anecdote, which illustrates this, taken from notes during one of the visits.

Visit 9 – “A boy called Adil (who had mainly related to the children by playing with their equipment rather over-enthusiastically) today sat and watched Amber and asked about her eyes. I said she had ‘poorly eyes’ and could not see. He was quite startled and said, ‘Not see? What can she do?’ I said she could hear and feel things, smell and taste things. He thought about this and then asked, ‘Not see?’ a few more times. I had earlier suggested he sing ‘Baa baa black sheep’ to Amber and he then started singing. Amber was smiling and I told him she liked it and he sang some more and said ‘smiling’. He was very gentle and it was quite moving to see.”

The Project Begins

In September 2002 the first school was ready and the first pupil in the resourced provision started in the nursery class. Scott is a little boy with a metabolic disorder who is fed by gastrostomy tube and wears a helmet because he is unsteady on his feet and unaware of danger. He also needed the helmet because he would frequently bang his head on the floor, when upset. He has severe language and learning difficulties. His statement gave him full-time support from a special needs assistant and a lunch-time supervisor. The advisory teacher, speech and language therapist and paediatric nurse all support his placement.

Scott loves nursery. He no longer bangs his head or shows other signs of distress. He tends to 'flit' from one activity to another, but is now spending more time on a wider variety of activities, e.g. playdough, water play and especially the home corner, where he loves to play with the other children and they love to play with him. He will now sit for the register and circle time, because he loves to be with the other children. His few Makaton signs have mushroomed and the other children have enjoyed learning signs. The class teacher and nursery nurse have an excellent relationship with Scott and plan the curriculum to include him. His special needs assistant gives just the right amount of support, encouraging other children to interact with him, as well as helping him to benefit from all the activities of the nursery. Targets are set through his Individual Education Plan and he is being assessed using observational reports, termly videos and the PIVATS assessment.

There will be more challenges as he goes through the school, and the curriculum will need to be adapted more extensively. Teachers have had some initial training in bringing more multi-sensory experiences into the curriculum, and this will be extended as Scott and other new children go through the school. Many of the typically developing children will also benefit from these methods.

How will Special School Staff React to Inclusion?

Inclusion means all children. Not just those who can 'cope' with the regular curriculum of a mainstream school. The reaction of the staff in the 5 schools that are becoming fully inclusive has been very positive. It is to be hoped that special school staff will also think positively about this kind of initiative. Perhaps they will find it difficult to avoid negative thinking. But they should embrace inclusion as a wonderful opportunity for the children. Many special schools run inclusion programmes, but very often these are underfunded and only involve the more able children in visits for a small part of the week. If a child is a full member of a mainstream class, they have far more opportunities to interact with other children. They belong to that class. If special school staff look on inclusion as an opportunity for severely disabled children, they can use their experience and expertise to help it to be successful. In Bolton, the special school for children with PMLD/SLD is involved in training for the inclusive schools. Staff visits between the schools have been arranged and children from the special school are going to have regular sessions at the inclusive schools.

A Parent's View

Many parents of children with severe or profound impairments may be anxious about a mainstream placement for their child. They may picture a classroom like the one they experienced at school and be unable to imagine their child there. In Bolton we are ensuring that the children will have the individual support they need and that the curriculum is adapted to be meaningful for them. The other fully inclusive schools will be able to take children in the next academic year. We hope that parents will learn to trust us to give their children an excellent education fully included with their mainstream peers. Scott's mother, Gina, is happy with her choice of Blackshaw Primary School:

"Scott is learning a lot in mainstream school, because he is copying the other children. When other children do something, like sitting on the carpet, he does it. He wants to join in all the activities. If he had been to a special school, I don't think he would have come on like this, because he wouldn't have been able to learn from the other children there. He is using a lot more Makaton signs. He is not talking, but being around children who can talk, not just make sounds like he can, is hopefully going to bring him on."

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INCLUDING CHILDREN IDENTIFIED AS HAVING PROFOUND AND MULTIPLE LEARNING DIFFICULTIES

Historically, we have seen that special schools have been a major resource in the education of children with special educational needs and the emphasis on de-segregation during the past 20 years has resulted in the inevitability of special schools realising new roles and functions in order to complement the inclusion process. Many links between special schools and their mainstream counterparts have been established since the Warnock Report (DES 1978), which stated that there was a new role needed for special schools and that the establishment of firm links between special and mainstream schools was required. However, whilst Governments, LEAs and schools are discovering new ways of promoting greater inclusion, the needs of pupils identified as having profound and multiple learning difficulties are often not being addressed and the inclusion process is in danger of making this minority group more isolated and marginalised than they have been in the past. Rose (2002) warns that whilst moving forward with the inclusion process, it is imperative that pupils with the most complex needs must be taken along as well, otherwise they are being denied their basic human rights. Although many would not argue against the moral value of inclusion, it is imperative that we build bridges between the rhetoric of ethical issues and the practicality of facilitating the inclusion of these 'hard cases' into the mainstream. We need to focus on the practicality of what actually works within inclusion and how we can include all children effectively.

Norfolk Park School in Sheffield specialises in educating children identified as having severe, complex and profound learning difficulties, aged between two and eleven years. Over the past 10 years our inclusive practices have evolved to meet the diverse needs of all the children within the school. We have developed a strategy for good inclusive practice by working closely with parents and children, teachers in mainstream schools and other professionals, providing support, advice and in-service training across Sheffield. Our flexible and adaptable approach has shaped the way in which we have defined our role as a special school and as such were highly praised by OFSTED in our school inspection, reporting that the school provides 'excellent support to enable pupils with a wide range of special educational needs to be included in mainstream schools' (2001).

The School's Inclusion Team is responsible for providing the opportunity for every pupil within the school to work alongside their mainstream peers in a variety of ways depending on individual needs. Some children are dually registered at Norfolk Park and their local mainstream school, with support, whilst others are supported in their own community school for one or two sessions per week. OFSTED reported that 'This not only contributes significantly to their learning but is also a significant factor in their personal and social development' (2001). In addition to this we have also made various links with local schools where part or whole classes join together to share numeracy and literacy hours, curriculum and topic work, social events and resources on a regular basis.

The core task of our inclusion team is to work closely with mainstream colleagues, striving to maximise inclusion and to offer the greatest possible learning opportunities for all students. This work is primarily a process of building relationships with mainstream colleagues and learning from experience in the field of inclusive education and within the context of relevant legislation, research and practice. The inclusion team's policy is:

- To provide opportunities for as many pupils from Norfolk Park School as possible to work and socialise alongside their mainstream peers in as many meaningful ways as possible, without disadvantaging any of the participants.
- To work closely with and offer support to mainstream schools, parents, special schools, support agencies, and the LEA to help increase the quality of inclusion throughout the city.

(Norfolk Park Inclusion Policy, December 2001)

We perceive inclusion at Norfolk Park School as a process through which we strive to gradually transfer resources, expertise, staff and pupils from segregated schools to appropriately supported and diverse mainstream schools. We view our inclusion programme as a way of opening doors and dispelling fears through experiencing first-hand the benefits that inclusive education brings to everyone involved.

When considering developing an Inclusion programme from within a special school, it is unlikely that any one model of inclusion will be adequate to meet the needs of all pupils. It is therefore more likely that a continuum of multiple models is experienced and Norfolk Park achieves this through the provision of a variety of activity-based links, offered at different levels in order to meet the very individual and complex needs of all our children. These Activity-Based Links include:

Level 1 – Dual Placements – this is when children attend both their local mainstream school and Norfolk Park and the split is generally about 60% attendance at the mainstream school and 40% at Norfolk Park.

Level 2 – Sessional Placements – children from Norfolk Park attend mainstream schools for one or two sessions a week. Most of these placements have been the child's local school, although some have been attending schools local to Norfolk Park.

Level 3 – Partnership Initiatives - We also work in close partnership with 2 mainstream schools, whereby we have regular curricular-based links with classes and children from both schools. This includes children from our school attending a partnership school for art, numeracy and literacy and their children joining us for PE, literacy and music. Children from these schools also regularly attend our school for special occasions, visiting artists and so forth.

We perceive the first step towards facilitating true inclusion must be in changing attitudes through positive experiences and building on what is practicable and possible within current practice and policy constraints. Tilstone (1998) warns that the attitudes of today are dependent not only on the contacts and experiences of the present, but are determined by the feelings, reactions and beliefs of the past and that these need to be challenged, otherwise they will continue to be handed down from one generation to another. My own experience has certainly borne witness to this, finding peers never having much of a problem accepting children from our school, but it is common for teachers to express an initial very real fear. Many apprehensive teachers have changed from being fearful to having a commitment to inclusive education, once they have experienced working with our children first-hand. One teacher told us:

'As an adult working with boisterous but healthy children I was very apprehensive about how I would cope seeing children with severe disabilities. I have found it a relief to know I can easily talk to and touch these children and smile at them and sing to them. In fact, it has made it easier for me to smile in a natural way and sometimes converse with disabled adults in wheelchairs in the streets and shopping centres.'

(Mainstream Nursery Teacher)

Another teacher told us:

'The prospect of working with a child from Norfolk Park was very daunting, but the reality was very different. The experience has been very enjoyable and it has helped me to address my own attitude towards disabled people in general.'

(Mainstream Primary Teacher)

Link schemes may provide an essential 'en-route' step towards inclusion (Jenkinson 1997) as can be seen from our own link schemes. For example, one child increased her time in mainstream from one to two sessions a week and is now dually placed, which means she attends her local mainstream school for three days a week and Norfolk Park School for two days a week. Another child was also dually placed with his local mainstream school and us and this has now resulted in his full-time attendance at the mainstream school.

Through experience, we have found that the groundwork undertaken prior to a placement and the continual ongoing support offered to the mainstream school helps to break down fear and prejudice and is an essential component to the relative success of such placements. With this in mind, we endeavour to share our inclusive

experiences with as wide an audience as possible and this has evolved into the provision of a Learning Centre at Norfolk Park. This Learning Centre offers much needed support for mainstream schools that include children with the most complex of needs throughout the city. Initiatives in this area include providing essential support for the schools, support assistants, teachers and families of children included in mainstream schools who would have otherwise attended Norfolk Park School. We also offer general support in the form of staff meetings, conferences, workshops, training sessions, etc. to professionals nationally as well as locally. Our latest initiative is the development of a resource library for the use of schools around the city to borrow specialist equipment including hardware, software, access devices and other appropriate resources.

All children are entitled to a broad and balanced curriculum, which includes experiencing a varied and expanding range of rich educational encounters which present them with fresh challenges. They are also entitled to prepare for life as adults and active citizens and should have the opportunity wherever possible to experience mainstream education through inclusion initiatives, such as those practiced by Norfolk Park School.

For inclusion to work in practice, it is essential that all involved benefit from the experience. Inclusion offers children identified as having profound and multiple learning difficulties opportunities to develop friendships with their mainstream counterparts and provides realistic life experiences that prepare them to live in the community. Once a child has been accepted and included into their mainstream school, the opportunity to be included into the wider community is enhanced and this may also promote a feeling of acceptance and belonging for the family as a whole, helping them to feel less isolated from their community.

The following quote from a parent of a child identified as having profound and multiple learning difficulties, powerfully describes the benefits of inclusion for all involved:

'Marsha learns how it feels to belong in class six. She sees how her friends run, dance, jump, sing, shout, argue, chatter. She learns how it feels to have friends who play with you. She learns how it feels to be with people who share with you, who care about you, who send Christmas cards to you. She learns about Ronald McDonald parties, Andy the Clown parties. Bouncy Castle parties.

She learns what it feels like to be included in the school choir, Christmas plays and school trips. Marsha learns how it feels to belong.

The children in Marsha's class learn about Marsha. They learn that not every child can run, dance, jump, shout. They learn that sometimes you have to communicate in a different way. They learn that just because a person can't do the things they do or act the way they act or sound the same as they sound, they still matter the way that Marsha matters, that they still count the way that Marsha counts.

They learn that Marsha too has feelings and that she too can be happy or sad. They learn how to care and to think about people other than themselves. They learn how to help and assist Marsha with her class work.

They learn how much harder Marsha has to try to do the wonderful things which they enjoy and take for granted. They learn how tough it must be, without being excluded from everyone's lives too.

(Hanson, L, 1996)

However, a child does not automatically become a fully accepted and respected member of the class overnight. Once a child identified as having profound and multiple learning difficulties is attending their local mainstream school, much work is needed to build upon the child being merely present in the classroom, towards attaining more meaningful inclusion. In order for this to happen, we have found that a child may need to progress through the following stages:

- **Present** - for the child with a disability to be present in the school, attending classes and social occasions
- **Welcomed** - for staff and pupils to positively welcome the child into the school
- **Known** - for the child to be known by name to staff and pupils and for them to be aware when the child is absent
- **Understanding** - for pupils to understand or obtain meaningful information from the child's unique mode of communication
- **Accepted** - for the child to be appreciated as a person with preferences and with an individual nature
- **Interaction** - for positive reciprocal interaction to occur between a child and other pupils
- **Friendships** - for relationships to develop through mutual respect and understanding
- **Valued** - realisation of the child's contributions to the class and school as a whole
- **Belonging** - for the child to participate and be included in the life of the school
- **Community** - through belonging to the school, the child becomes part of the wider community

In order to progress successfully through these stages and for all students to be welcomed into their local schools on an equal basis regardless of difference, there needs to be a significant change in both mainstream and special school cultures in relation to attitudes and perceptions about including disabled children. Special schools need to complement the inclusion process and contribute to this profound cultural shift through diversification and developing mutually supportive links and partnerships with their mainstream colleagues. Once schools begin working together to increase their capacity to respond to pupil diversity and promote greater participation for all pupils, the quality and flexibility of teaching approaches will increase and further extend the process towards achieving more meaningful inclusion. As stated in the DfES statutory guidance *Inclusive Schooling*:

“All special schools must be outward looking centres of excellence working with their mainstream partners and other special schools to support the development of inclusion.” (DfES, 2001)

In order to achieve this, special schools need to have a clear vision for working towards a more inclusive education for their pupils and a focus on the practicality of what actually works within inclusion is essential. Support and training for mainstream schools to enhance their awareness and confidence in including children with the most complex needs is critical if the success of including this potentially marginalized group is to be realised. We need to share our experiences and knowledge of the specialist adaptations required for pupils who experience severe difficulties in learning with our mainstream counterparts, as this is instrumental in changing values, policies and practices to enable barriers to participation and learning to be overcome. It is in the mutual sharing of the collective wealth of diverse experiences that the key to providing an equitable educational system that incorporates both the commonality and uniqueness of all learners can be found.

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DISABLED CHILDREN HAVE A RIGHT TO PLAY

The Disability Discrimination Act

in the lead up to the full implementation of the Disability Discrimination Act in 2004, how can play and leisure providers begin to plan for the inclusion of disabled children in their settings?

The Disability Discrimination Act (introduced in 1995) is the most significant piece of legislation affecting disabled people – adults and children – in the UK. The Act defines disability as a “physical or mental impairment which has a substantial and long-term adverse effect on a person’s ability to carry out normal day to day activities.”

The section of the Act that relates directly to play and leisure is *Part III: Access to Goods and Services*, the first stage of which came into force in December 1996. At this stage the Act made it illegal to treat a disabled person less favourably than a non-disabled person without justification for a reason related to their impairment. The second stage of Part III came into force in October 1999. The Act applies to:

- Play areas and playgrounds in public parks
- Private and voluntary playgroups, playgrounds and nurseries
- LEA day nurseries, family centres and out of school clubs which are not part of a school
- Non-statutory youth services (i.e. Scouts, Brownies, youth groups)
- Indoor and outdoor adventure playgrounds
- Leisure centres

The core duty of the Act is to make ‘reasonable adjustments’ to the way services are provided – that is take positive steps to ensure that services are accessible to disabled children and young people by:

- changing any policies, practices and procedures that discriminate against disabled people;
- providing auxiliary aids and services (such as a sign language interpreter or information on tape) to enable or make it easier for disabled people to use the service;
- making services available by reasonable alternative methods where a physical feature is a barrier.

Services cannot have blanket policies about excluding children with particular impairments (i.e. ‘we cannot accommodate children with profound and multiple learning difficulties’ or ‘we do not accept children with epilepsy or allergies’). They are expected to consider what support a child might need and provide it. If not, they must demonstrate why they cannot make reasonable adjustments in order to accommodate that child, or that it contravenes their health and safety regulations.

The final phase – 2004

The definition of ‘reasonable’ is crucial. Having access to funding to make changes forms part of the analysis as to whether change is ‘reasonable’. Thus a small provider with limited resources will not be expected to respond in the same way as a large provider.

Action Plans – Planning for 2004

The DDA duties are anticipatory, so it will be essential for all providers of play services to develop action plans to demonstrate that they are progressively working towards greater access and inclusion. In other words, you can't just wait until a disabled child comes along to start making changes – you need to start planning now!

In anticipation of the implementation of the final phase, play providers will have to incorporate access planning into all new and improved play provision. One of the best ways of doing this is to carry out an access audit of your current provision (contact the Centre for Accessible Environments for a register of qualified access consultants – go to: www.cae.org.uk). But remember, access is not just about physical access but also about communication, information and above all, training.

On a practical level training for inclusion might include finding out about relevant legislation and how this will affect your project, looking at how to adapt games and activities so that all children can join in, or learning some basic sign language so that children who use this method of communication can participate. The charity Kidsactive runs a range of training courses aimed at overcoming barriers to inclusion for staff at all levels.

Kidsactive

As part of Kidsactive's strategic development to support the play and childcare sector, the charity has secured funding from the Sure Start Early Years and Childcare Unit of the Department for Education and Skills (DfES) to run the Playwork Inclusion Project (PIP). Under PIP Kidsactive has devised a major new training course 'Planning Inclusive Play', and launched the National Inclusive Play Network which provides members with regular e-bulletins and regional seminars on inclusive play.

The Network is creating a central database of organizations and individuals who are committed to inclusion – yet feel the need for some support and encouragement. As Joanna Ryam, PIP Project Manager says, "Kidsactive is well aware that the inclusion of disabled children in play can appear to present challenges. But we are also aware of the many creative ways that playworkers and play settings are already working inclusively. By providing a central focus for information on inclusive play – and encouraging contact between practitioners, settings, trainers or local play services, the NIP Network can support inclusion in settings throughout the country and keep members in touch with new inclusive projects, events, training, publications, legislation and policies."

Rachel Scott

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For further information on Kidsactive training courses or to join the NIP network, send your e-mail details to: pip@Kidsactive.org.uk

Footnote

Kidsactive will be merging with the charity KIDS in the autumn. It is expected that all aspects of Kidsactive's operation which includes six adventure playgrounds in London and the National Development Division which runs the PIP programme and provides training, consultancy and publications, will be incorporated within KIDS.

ONE TREE – MANY BRANCHES

1st Clent (Sunfield) Guides

Seven years ago, a fellow member of staff at Sunfield, and like myself, also a Guider, said 'wasn't it a pity the girls didn't go to Guides, especially as some of the boys managed to go to Scouts.' That remark was the starting point, and Sunfield Guide Unit was formed.

I have been involved with Guiding since, at the age of 7, I became a Leprechaun in the 1st Chigwell Brownies. Over the years I have gained a great deal of fun and knowledge through Guiding, and have seen not only the enjoyment that my own daughters gained from the movement, but also the fun, socializing and achievements gained by girls in Rainbows, Brownies and Guides.

Sunfield School is a residential school for young people with severe and complex learning difficulties and profound Autistic Spectrum Disorders. Many have additional behavioural problems. It would not, therefore, be very easy for our girls to integrate into mainstream units. In common with many 'volunteer' movements there are not enough adults to 'go round' and for our Guides to enjoy and gain from Guiding they need support and understanding. Support which is difficult to provide in a busy Unit of up to 36 girls, and understanding which many not be available when an everyday occurrence causes that special Guide to 'flip'.

We started with 10 girls, and two patrols – Poppy and Daffodil. Over the years numbers have varied between 8 and 12 and we have abandoned the patrols, functioning as a single unit – not a huge Unit but a very special one!

We do however have links with other members of the movement. Thinking Day was celebrated at Sunfield with Rainbows, Brownies, Guides and Leaders from the District all joining in a song and dance service, with each Unit contributing an item. Our girls performed a simple dance choreographed by a staff member. A member of the audience came to me afterwards to say that the girls' contribution made Thinking Day truly meaningful for him. We have also entertained local Brownie Units, but forming links with Units of similar ages is not so easy.

One of the Guide Laws states 'a Guide faces challenges and learns from her experiences.' During meetings the girls are constantly doing just this. Putting up a tent is quite a challenge, following instructions, learning to wait and working as a team before you can enjoy the picnic inside, and then waiting for all the Guides to be out of the tent BEFORE you let the guy ropes down! Learning about the world of Guiding through making a fruit salad; learning how to sew, and thread a needle! Learning to use an iron to 'fix' a dye on a handkerchief; learning to play together and help each other.

Another Guide Law says 'a Guide is helpful and uses her time and abilities wisely'. The girls have helped with Worcestershire County's Commissioner's challenge to raise funds for the new Acorn Hospice. They made biscuits and hosted a coffee morning at school, which was well supported by their fellow pupils.

We do not have a Unit flag, but four years ago we designed, with the Guides, our own banner which they were all involved in sewing. It has pride of place on the top corridor at school, on the Guide notice board.

At the moment they are all working through 26 challenges, one for each letter of the alphabet, which range from cutting an apple to painting a flower pot, from baking cakes to managing a zip. Each 'challenge' represents a personal achievement for that girl, and is extending her abilities.

Making the Promise is an important element in Guiding. It is probably the most difficult element for any Unit. How do you explain 'love my God' 'serve my Queen and my country'? By practical means, by

encouraging friendship, helpfulness and thoughtfulness. By encouraging respect for herself, her community and the environment.

When one of our Guides makes her Promise, she does so in the manner most meaningful to her. She may sign, use a Lotto match, use pointing or speak some of the words. It may be a combination of all four. At our last Promise ceremony on Guide signed the Promise unaided, another copied an adult signing and two girls placed matching Lotto cards onto the Promise as it was spoken. Seeing the concentration on their faces, no one could doubt their appreciation of the ceremony and the feeling of doing 'something special.'

The Guide Promise starts with the words 'I will do my best' and it is this element which is the basis of each of our meetings. Whatever we are doing on that night, the girls are encouraged to do their best but to have fun doing it.

Sandra Allen

Guider in Charge, 1st Clent Guides

Senior Speech and Language Therapist, Sunfield School

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MUSN'T GRUMBLE: CAN'T GRUMBLE

“I couldn't say anything as I knew my mum needed me to go into respite”

These are the words of Kate at 19 when looking back on why she never said anything about the short breaks unit she had gone to from the age of 10. She didn't like the group of young people she was booked in with and hardly got any sleep when she was there. The staff seemed to serve up chips every night when she was trying hard to keep to a healthy eating plan.

From the age of about 14 Kate had been included in her 6 monthly reviews. She had to try to tell a large group of adults, including her mum what she liked and what she didn't like about the short breaks. She was aware that her mum had a bad back and had told social workers this was from lifting her before a hoist was installed at home. Kate had also picked up from overheard discussions that if she didn't go to the short break unit she would have to go away to residential school. Not surprisingly, she couldn't tell her key worker or her mum what she thought about the unit. In fact if she had, the unit staff might have easily been able to make some changes.

Kate helps us understand one of the many barriers facing disabled children when services don't work as well as they could or should. She is able to communicate using speech but still wasn't able to voice her concerns. For children with a severe or profound learning disability there are many other barriers. They may, for example, not have a communication system that allows them to complain. It is only very recently that symbols and signs for abuse have been added to some communication systems.

All children communicate their views about the services that they use and children with profound and multiple learning disabilities are no exception. The difference is in the way that their concerns or even distress are communicated. This is likely to be through non-speech forms of communication. Some of this will be easy to detect such as turning away from an activity, pushing out of a standing frame, or shouting. For some children their communications may well be much more subtle, and include withdrawing eye-contact, facial expressions and small changes in alertness.

Children with severe learning disabilities pick up from parents and professionals the scarcity of resources and the lack of choice. Even if the after-school club isn't meeting your needs for intimate care very well it may still be the only club in the area. For many of these children it is a case of put up or shut up. Children with a learning disability are also particularly vulnerable to leading questions. Asked "you like coming here don't you" they are most likely to nod in assent. They are not asked their views in ways that encourages them to answer in the negative.

These children are often long term users of a range of support services, for example short breaks and domiciliary care as well as holiday playschemes. They are also more likely than other children to spend time in hospital clinics or as in-patients. For the children who may have the greatest need of a robust complaints system there is however very often the least access to such a system, as these complaints processes are not adapted for their needs.

For the parents of these children there are also barriers. On the one hand they are expected to be 'grateful recipients' of services and on the other hand regarded as demanding and difficult if they raise any concerns or make a complaint on behalf of their child. For most severely disabled children, parents are their strongest advocates. Children themselves will typically only be able to access complaints procedures through their parents. These parents in turn need support in translating their child's right to complain into effective action on their behalf.

The issue of complaints is always going to be a difficult one for staff especially when they are working in services that are already under pressure. Many staff do not feel that they have the tools or skills to communicate effectively with children about choices, let alone concerns or complaints. Some of the methodology that has been developed, for example, in children's homes, has not yet reached the services that disabled children use. There have been some projects that have developed an approach that opens up communication for staff working with disabled children but does not go as far as supporting work on concerns and complaints. Staff need to be working within a culture that encourages complaints alongside compliments and also be supported by managers to uphold the rights of children to complain when services do not work properly.

Although virtually all services are now required to have in place a complaints procedure there has been very limited progress in making these procedures accessible to disabled children. Before these children can be part of a formal complaints process they need to know that they have a right to express their views about services and have their concerns addressed. The focus in some areas on developing an 'accessible leaflet' that explains complaints to disabled children is misplaced if these children use services that do not listen to their concerns and act to change the service to meet these concerns.

Mencap's LISTEN UP pack supports children, staff and parents in responding to concerns and complaints. For children, there are posters and complaints cards to customize as well as a board-game to play. For staff there is a training video and also a workbook. For parents there is a leaflet that explains their child's right to complain and how to access the complaints system. This pack does not try answer all the questions but does give staff tools to help them work with children and parents in this sensitive area.

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LISTEN UP packs are available free from Mencap by calling 0808 808 1111 or email at information@mencap.org.uk or can be ordered online at www.mencap.org.uk

INCLUSION FOR PUPILS WHO EXPERIENCE PMLD

I am currently writing up my research for the dissertation of an M.Ed. This research is looking at inclusion opportunities in mainstream primary schools for pupils who experience PMLD. As part of the study I have been privileged to visit many schools in a selection of Local Education Authorities across England and in the process met a number of amazing people, including parents, Learning Support Assistants, teaching staff, including school management teams, LEA staff and of course, some wonderful young people too.

This contribution to PMLD Link offers

- an overview of my work
- an insight into PMLD Inclusion in British Columbia, Canada
- some thoughts about current trends
- an invitation to contribute to a celebration of good work !

Research overview

Three years ago I wrote an essay entitled "Can a pupil who experiences PMLD be included in a mainstream setting ?" which was submitted as part of my M.Ed. At that point I interviewed a cross section of school staff and members of the inter-professional network within the LEA where I work. The findings and responses from this small scale survey lead to a developing interest in the education of pupils who experience PMLD. At this time I was also part of a working group of practitioners (Dorchester Curriculum Group) who were looking at differentiating the curriculum at P Levels 1-3. Our work was incorporated into the general guidelines from *Planning, teaching and assessing the curriculum for pupils with learning difficulties* (QCA,2001) and subsequently lead us on to showing how access to a curriculum that is holistic and goes beyond the National Curriculum can be made meaningful for pupils who experience PMLD. This was then published as *Towards a Curriculum for All* (Dorchester Curriculum Group, 2001).

This work has led me on to my current study, which has had two research phases. Initially, I surveyed all 150 LEAs in England to find out which of their mainstream schools were involved in inclusion placements for pupils who experience PMLD (at any level). I have subsequently visited a number of different schools and LEAs to observe such inclusion placements, and I have also interviewed senior LEA staff, Headteachers, parents, teaching and support staff to find out how these inclusion placements were originally planned and how the financial, ethical and practical difficulties have all been resolved.

An insight into PMLD Inclusion in British Columbia, Canada

In April this year, I was invited to visit the Provincial Integration Support Programme (PISP) which serves the British Columbia Ministry of Education, Canada. I met Terry Wendorf, who co-ordinates the programme and was able to learn about how pupils who experience PMLD are effectively included in their local mainstream school. She shared a video with me, called *Integration : Meeting the Challenge*. This shows four examples of pupils who experience PMLD in different age bands in their mainstream schools. I have brought back a copy to England and have since used it for sharing with other staff. One of the many points to come out of the video, is evidence of how other (mainstream) pupils are encouraged and enabled to be proactive in their responses to and communication with their PMLD peers, as part of an ethos of inclusion which is the norm and not the exception.

Terry also gave me an overview of how the inclusion support programme originated (when staff in special schools were required to disseminate their expertise by establishing SEN support networks for staff in mainstream schools) and how it now supports an even wider range of SEN in mainstream schools. This process has been developing for over ten years and Terry described the way in which schools have had to respond to changes in the political climate in British Columbia and Canada.

Terry also co-ordinates an online inclusion learning programme from the Simon Fraser University and the University of British Columbia. This summer there is opportunity to participate in a course entitled *Educating Students With Severe Multiple Disabilities*. This course is designed to mentor and support experienced teachers who are working with a student with severe or profound multiple physical and cognitive disabilities.

Some thoughts about inclusion trends in England

Can inclusion in mainstream schools be relevant for pupils who experience PMLD? I acknowledge that for some people, parents, educational and local authority staff, the concept of inclusion for pupils who experience PMLD is difficult to invest in, both morally and practically. There are others, whose views are more in line with the inclusion proactivists, such as the CSIE, who would say that pupils who experience PMLD have a right for full time education with their peers from their own local community. In between both poles of view, lies a wide continuum of inclusive opportunity, ranging from pupils who experience PMLD sharing an occasional assembly at their local mainstream school, links for projects between special and mainstream schools, through to longer term dual placements.

I like the idea of “unfolding” a pupil’s learning identity as suggested by Erica Brown (1998)

“Children bring into school a wholly unexplored, radically unpredictable identity. To educate, is to unfold that identity – to unfold it with utmost delicacy, recognising that it is the most precious resource, the true wealth of the human nation “

This, to me, is the essence of what effective inclusion for pupils who experience PMLD is all about. Offering pupils of any ability opportunities to share in that process of unfolding and to then help them grow together. When I worked with colleagues from other local (Dorset) special schools in writing “Towards a Curriculum for All” (Dorchester Curriculum Group 2001) we believed that effective inclusion should involve :

Entitlement because all pupils are entitled to equality of opportunity, and pupils who experience PMLD have just as much right to high quality shared learning experiences as other pupils. The success of these shared learning experiences will ultimately be dependant on the quality of interactions within the learning environment.

Empowerment because all pupils are pupils first, and have a basic human need for realising their self-worth and raising their self-esteem through sharing success. Pupils who experience PMLD are no different and the authors suggest that inclusion for these pupils would be a process of empowerment towards greater awareness of the world around them.

Enablement because all pupils have the potential to learn from quality interactive learning experiences. Inclusion for pupils who experience PMLD has the potential to enable them to access their learning environment and interact with their peers.

I have observed a number of different mainstream inclusion placements for pupils who experience

PMLD, most of which have been in Reception and Key Stage 1 classes, and most as a result of parental choice. Such placements have been fixed term, i.e. for an agreed and planned session (e.g. Music, Literacy) at a specific time during the school day. I acknowledge the very real problems associated with funding and resourcing such placements and perhaps most importantly, ensuring effective teaching and differentiation within them. There are far fewer examples of pupils who experience PMLD being included and registered in their local mainstream school for more than 51% of their time (I have observed one such placement)

It is interesting to refer back to the British Columbia model where pupils who experience PMLD are included in their local mainstream schools for 100% of their time and the necessary levels of support from the interprofessional network for staff training and individual programmes, is provided by external support teams.

However, I feel it is not enough, simply to enable pupils who experience PMLD to communicate with and within their learning environment, by whatever means of augmentative communication is appropriate for each individual. Inclusion is a dynamic process, and enabling everyone else in the learning environment to communicate with the pupil with PMLD is equally as important.

This means structuring the day so that the pupil with PMLD and his/her mainstream peers are ready to interact with each other whenever it is appropriate to do so on their terms, not the schools. For example, if a pupil who experiences PMLD needs individualised time for personal care, or is tired or uncomfortable, the inclusion placement must be flexible enough to accommodate the need for this at any time during the placement and/or at any time during the day. I consider myself very fortunate to have observed a number of mainstream inclusion opportunities where the pupil with PMLD is interacting very well with his/her peers, achieving across the board on his/her IEP communication targets. But more importantly, the ethos of raising expectations for all pupils comes across clearly in these placements because staff have gone out of their way to enable the children in their own classes to learn how to communicate with their peer with PMLD.

Many schools have come a long way in developing their inclusive practice since the guidelines of *Meeting Special Educational Needs : a programme of action* were published by the DfEE in 1998. Instrumental in this has been the work undertaken by LEAs and mainstream schools when using the *Index for Inclusion* (Ainscow & Booth, 2000) in helping them to address their response to SEN issues and develop their own inclusive practice. Developments in policy have filtered through to practice, almost by degree of educational need, so that now, in 2003, schools that have been proactive in developing their inclusive practice feel more able to manage pupils with higher levels of need. Not that long ago, inclusion used to be called integration, but we have moved on since then to a better understanding of what constitutes a meaningful learning experience, for a pupil of any ability. Pupils who experience SLD or MLD, or indeed any number of increasingly identified SpLD are now far more likely to have some level of inclusion in their local registration mainstream school. The term "barriers to learning" was used in the *Index for Inclusion* (Ainscow & Booth, 2000) to describe the limitations in opportunities to achieve and/or succeed in a pupil's learning environment.

The concept of removing 'barriers to learning' offered a framework in which schools could address the learning needs of all their pupils, especially those with SEN, and more recently, schools and LEAs have been legally obliged to respond to the Special Educational Needs and Disability Act (2001). This new legislation requires LEAs and schools in England and Wales to draw up accessibility strategies and accessibility plans respectively, for improved access to the curriculum, to physical parameters (school buildings etc) and to the dissemination of information. In preparation for, and since the revised *Code of Practice* (DfES,2001) came into effect in January

2002, LEAs and schools have had to further develop their responses to children with a wider range of learning needs. As schools have developed their own inclusive practice by virtue of their responses to these government initiatives, so their ability to respond to the learning needs of pupils with an increasingly wider range of special educational needs has improved.

However, I am also aware of examples of inclusive practice involving pupils who experience PMLD that have not been as successful as they could have been. This is due mainly to inclusion policy decisions being taken by senior management both in LEAs and in schools, that have not been implemented with careful enough planning, or indeed without the appropriate levels of funding for support. Such inclusion placements revert back to integration, and have not worked for pupils who experience PMLD. The policy for inclusion may have been well-intended, but inclusion placements at any level need to be shared and "owned" by many different stakeholders, including parents, teaching and support staff, and members of the associated professional networks, all of which is absolutely crucial for any pupil with SEN, especially one who experiences PMLD.

I have observed a number of examples of successful inclusion placements in mainstream schools for pupils who experience PMLD. The smiles and responses from all involved, pupils, teaching and support staff in particular, are evidence that inclusion for pupils who experience PMLD can work and can be extremely rewarding. This is not to devalue the hard work and frustrations when such placements are not successful, but the values of an inclusive society are fostered in the ethos of an inclusive class - teach the children of today the value of tolerance and respect for others in the world that they will inherit tomorrow.

An invitation to contribute to a celebration of good work !

I am sure that there are many more examples of good practice in schools and school communities where there is effective inclusive practice for pupils who experience PMLD. I would like to suggest that there is a forum to celebrate such examples and that perhaps one LEA or other body might like to host a national conference to do so. The focus would be on inclusion, in a variety of different settings, and the celebration of the many achievements of pupils who experience PMLD and the children around them. I would be more than happy to co-ordinate such an event.

Stephen Mason

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MEMORIES OF CLEVES

Cleeves Primary School is a two-form entry, mainstream school in the London Borough of Newham. The school includes four children in each age-group with a high level of support needs, including children with profound and multiple learning difficulties. I have visited Cleves School on a number of occasions with other teachers, headteachers and officers from Bolton, and we have all been extremely impressed by their work.

The school has just celebrated its tenth anniversary as a very successful truly inclusive school. They have an excellent and entertaining website: www.cleves.newham.sch.uk, where you can learn about the school; see pictures and video of the children; and listen to the song they sang to celebrate their anniversary.

Some children from Year 6, leaving Cleves this summer, decided they would like to write for PMLD-Link, what the school has meant for them.

Cath Ryde

Our Unique School

I have lots of great memories of Cleves Primary School. I came to this school in year 5; it was a lovely experience because we moved to different classes unlike my previous school, there are lots of curriculum rooms like in secondary school!

My earliest memory was of special needs children working happily with each other. The school is based on one floor so that children in wheelchairs can move around the school.

I noticed that the school cared a lot for children with special needs and other cultures. They had activity rooms such as sensory rooms, little room, soft play and others. My first experience was enjoyable because I never had been in rooms like these: they were great for all children.

On my first day I met a lot of teachers because we moved around a lot. I enjoyed coming to Cleves Primary School but I am leaving so I'll miss everyone.

By Yasmin Parvez

Cleves School

My school has helped me in lots of ways. I have been happy learning all the things that have been on offer. I have learnt interesting things in science/Maths/literacy and have really liked being in all of my groups.

I will have good and kind memories of helping Brennan at lunch-times and in literacy and numeracy. There are always friends to be made at Cleves! The school has taught me that everyone is really the same and that you should always help one another.

My early memories are of my 'base' playing with the parachute in the park, and the teachers joining in as well. The teachers and head-teachers are all known by their first names. We are all part of a team.

In the Cleves celebration a CD was made and sold hundreds of copies. The video is brilliant. The video shows the school working together with lots of tuneful singing by our choir too.

In conclusion I would recommend Cleves to everybody if you want to achieve.

By Brett

My Cleves Experience

Cleves is the best school in the world! Everyone is so friendly and fun to be with. I have been here since KS1 and have enjoyed everyday!!

I have made lots of friends during my time here who will remain friends with me for a long time.

There are many children at Cleves with disabilities. I have learned that we are all people and whatever your disability is you are accepted completely at Cleves. I enjoy going with my friends to the sensory room and ball-pool and helping them in other areas too. We are all a team.

The staff are all called by their first names; it is cool. I find them easy to talk to and friendly. Everyone helps each other to learn and have fun.

It is definitely a unique school.

By Shannon Fogg

Cleves

This is Cleves school; the best school in the world! and its got the best teachers! My name is Grant the reporter; I go to Cleves and it is good but this is my last 3 days!! The last 8 years have been so cool I will go to Brampton next.

Cleves makes me reel happy because I am included in lots of different fun stuff! – I like ICT and Science and like literacy. All the lessons have things which I can do ... I like that. Sometimes I get rewarded by using the computer ... when I am good. The computer helps me to learn.

Cleves is great because we can choose the stuff play.

By Grant Reid

Memories of Cleves

I will miss everything about the school, particularly my friends and teachers. I have always felt happy and comfortable here. I have learnt lots of skills – including football skills and basket ball skills.

The school assembly is when we all get together and celebrate our week. There is lots of singing and this is when people get awarded for their achievements from throughout the week. I will remember the performances by the choir and children dancing.

Our school is amazing ... it is all on one level (so you don't get lost!) it helps people to get around it safely. There is lots of fun stuff for all the children to help them learn; things like the new sensory room and ball-pool are great for my friends who need support.

Sometimes I get to go to soft-play which is excellent. We are all part of a team and help friends to learn in different ways.

I like to go to different rooms to learn each day and meet the different teachers. My best memories will always be of Cleves Primary School!

By Mustaq Ahmed

Our Unique School

I started Cleves in reception and have experienced loads of good things that have happened here! - Such as - sports, friendship, education and most of all the talents here.

One of my memories has to be that Cleves has treated all its students in the same way, with what ever need they have.

The things I would say Cleves is best known as is that no matter what need a child has, or where they came from they know that child has a right to attend any school.

At most schools children have to stay in their class the whole day with the same teacher but not at Cleves!

As most children have a fun playtime so do special needs children. For the special needs children there have been rooms made especially for them. There is a sensory room, little room, soft play and many more.

Cleves has a variety of achievements for everyone such as - if you get a 5 certificate you get a £5 pound book token. I am leaving Cleves now I'm in year 6 I'll miss the school and everyone here!!!!!!!

Samina Hamid

Cleves Memories

Hi There! my name is Saflya. I arrived in this country from Sri-Lanka a few years ago and went to Cleves two weeks after arriving in this country.

I had been to many schools before arriving here, but Cleves remains undoubtedly the best! I remember the children crowding around and staring at me. I felt nervous - but they all wanted to, and became ... my friends!

Every child is accepted at Cleves; children from different backgrounds/cultures and with a huge range of disabilities.

Personally, I think Cleves is very supportive. We are taught and discuss respect for each other and there is always a relaxed atmosphere of enjoyment. At Cleves we rotate around and go to different areas for our lessons. It makes things much more interesting. I like the different activities which are continued at lunchtimes and after school; PE/Dance for example.

The diaries help the children and adults in the wing. We can talk about what we have enjoyed and share things with our great base-teachers! If you work really hard and gain certificates you can 'win' a five pound book-token.

I feel supported in everything I do; it helps me to learn a lot.

I will take away fantastic memories of the school - and will always have a copy of the school CD which I took part in.
Bye!!!

Saflya - Aged 11

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THE IMPLICATIONS OF PICA FOR PEOPLE WITH A LEARNING DISABILITY AND THEIR CARERS

This article is based on an assignment submitted in the course of studying for a Masters degree in Learning Disability Studies at the University of Birmingham Medical School, and describes the background information on pica and methods of management provided to carers with particular reference to a residential service-user who, for confidentiality reasons, will be referred to as Amy.

Due to an increase in the amount of pica exhibited by Amy, we needed more information about the condition. In my assignment I aimed to apply information gained from reviewing relevant research and from collaboration with a multi-disciplinary group to improve understanding and delivery of the service we provide for her.

Pica can be defined as the persistent eating of inedible or inappropriate items. It may be described as 'specific' if only one type of item is eaten or as 'generalised' if indiscriminate. The diagnostic criteria for pica laid down in the *Diagnostic and Statistical Manual of Mental Disorders* are as follows:

- persistent eating of non-nutritive substances for a period of at least one month;
- the eating of non-nutritive substances inappropriate to the developmental level;
- the eating behaviour is not part of a culturally sanctioned practice;
- the eating behaviour occurs exclusively during the course of another mental disorder (e.g. mental retardation, pervasive developmental disorder, schizophrenia), and is sufficiently severe to warrant independent clinical attention.

It is important to note that what some view as pica may be considered 'normal' to others. Although this statement has been validated on a cultural basis it is not well recognized within western culture, which appears to draw a fine line around this area. An example would be that the millions of individuals who chew their pencils on a regular basis for a longer period than one month are not classed as having pica, yet individuals with intellectual disabilities chewing wood are.

Although Pica can be found in people without intellectual disabilities, e.g. pregnant women, this article will focus on people with intellectual disabilities only. Despite the fact that pica has been reported to occur in a significant proportion of individuals with intellectual disabilities (Ali, 2001), information regarding this area remains sparse. Most staff members questioned (ranging from support workers to managers), knew what pica was but were vague about treatment/management due to the huge variability in its appearance as well as the large differences in its perceived importance.

I found that much of the research on pica in individuals with learning disabilities was limited to potentially life-threatening cases, whereas in my own experience non life-threatening cases are also cause for concern, as pica may have unknown repercussions in the long term or may escalate into a more dangerous behaviour if appropriate support is not obtained. This is why I have focused on pica that is not immediately classed as 'life-threatening'

Prevalence

Prevalence rates vary from 0.3-25% with the lower levels being found in the community and the higher levels in institutions, as noted by Ali (2001). She notes that some of this variation is due to different definitions of pica and the use of different populations. This tallies with the finding that pica is more often encountered in individuals with severe/profound intellectual disability (Hardan and Sahl 1997). The definition of pica used here was chosen because it covered both food and non-food related items, which are both ingested by Amy.

Case Study

Amy is a 20 year-old young lady with autism, profound learning disabilities and severe challenging behaviour who suffers from generalized pica behaviour. Amy is non-verbal and communicates mainly through use of a few Makaton signs combined with gestures, body language and facial expressions. She also communicates her needs through challenging behaviour at times. Amy will ingest a variety of items ranging from foliage to faeces.

She tends to eat items she encounters (ease of accessibility) such as leaves when walking past hedges, or soap powder when doing the laundry. She will also ingest rubbish (e.g. bottle tops or used chewing gum) especially when out in the community. Amy suffers from chronic bowel problems and is currently prescribed several laxatives on a daily basis.

Amy will become aggressive if she is prevented from obtaining the item she is after. Although this has resulted in some pinches or bites to staff, this is generally manageable. Difficulties usually occur trying to get Amy to spit the item out of her mouth and with most staff she will generally swallow it in preference to spitting it out. She will occasionally hand the item to staff, this varies between staff (occurs more often with firm, experienced staff) and the item being chewed (items such as paper or plastic are more likely to be handed to staff whereas used chewing gum will be swallowed).

To aid her digestion, Amy was placed on a high fibre vegetarian diet and she sees an osteopath weekly. Due to Amy's complex needs, it is difficult to judge her consent to the various changes. She tolerates the osteopathy sessions which involve manipulation of the entire body (based on a whole person approach), and the laxatives, and as a result is less constipated as well as less anxious about using the toilet. This can be measured by a reduction in her self-injury as compared to self-injury prior to the introduction of the treatments. The removal of meat from her diet is more of a dilemma as Amy previously enjoyed meat. Her enjoyment of meat substitutes is currently being explored.

Aetiology

Actual causes of pica are unknown but there are several theories.

Nutritional theory suggests that pica is caused by a mineral deficiency and Ali (2001) notes several studies which found that pica was reduced in subjects who were given supplements. However other studies have found no links between the two and Swift et al (1999) point out that it is possible that pica could cause the mineral deficiency (by preventing absorption of the minerals or not following a proper diet). Supplementing people's diets in order to remove this possibility may not be beneficial (and could even be harmful) therefore medical advice should always be sought.

Although Amy has exhibited pica for several years, it is conceivable that the recent rise in pica could result from one or a combination of certain factors. She has recently been seriously ill and could be using this as a coping mechanism and she has also been placed on a vegetarian diet in the last year to reduce her constipation, which may have affected her overall mineral balance.

Developmental theory suggests that pica is a result of individuals being unable to discriminate between food and non-food but this is disproved by the obsession with which certain items are chosen, leading to aggression if the individual is prevented from obtaining them (Swift et al 1999). The same study also found that almost a third of the individuals with pica preferred a single item suggesting individuals with intellectual disabilities are able to discriminate between different items contrary to popular belief. In Amy's case she appears to have preferences for certain items over others (even similar coloured items) but it is difficult to say whether her preference indicates that she has the ability to discriminate in general.

Psychological theory implies that pica is a behavioural response to stress similar to addictions such as smoking or drinking. In fact a study by Tewari et al (1995) recommended a reassessment for patients whose pica consisted of cigarette ends and suggested the possibility of using a controlled nicotine substitution (i.e. similar to the 'nicorette patch' system used by people trying to give up smoking). The study involved a survey of a learning disability hospital in which 25/246 residents had pica. Information was gained primarily from the keyworkers via interview and the scoring of certain profiles. No controls were used. Despite some limitations noted by the authors, including limited generalisability of subjects and the fact that neither validity nor reliability of the instruments could be tested, the study proposes several points which need considering when looking at pica in the wider population. This included the difficulties with the definition's use of the word 'ingestion' as not all individuals swallow the item. They suggest that 'mouthing of objects' might be preferable. They also note that boredom particularly in people with autism who are more likely to withdraw themselves when faced with uninteresting activities may act as a maintaining factor.

Based on my observations of individuals exhibiting pica within the organization, I think Amy's pica is related to her need for sensory stimulation. This is backed by her reduced levels of pica when stimulated (e.g. favourite fast music videos) and her increased pica when waiting or in a low-key session. Comfort eating also increases when bored for some individuals. Although this does not explain all of her incidents of pica, it may account for a large share. The possibility that her pica is maintained by consequences, e.g. attention, has also been implied by some staff. However, Amy regularly exhibits pica while alone in her room, hence the need for constant supervision, suggesting this is not the case. This would also correspond with research by Piazz et al (2002) which indicates that pica is automatically reinforced, for example by sensory consequences and is not affected by social interaction. Amy generally shows her need for social interaction by slapping nearby individuals who are getting some form of interaction at that particular moment. So, although pica may be an alternative way of communicating this need, this seems less likely.

Another possibility is that her pica may be a by-product of her need to remove clutter (a common feature of autism) as appears to be the case with another of our service-users. However, this again seems unlikely as Amy has definite preferences and will not pick up certain things even when they are within her immediate vicinity.

Consequences

Consequences of pica can range from nothing to minor conditions such as bad breath and minor stomach upsets to life-threatening or fatal conditions such as intestinal obstruction. Therefore it is hardly surprising that the perceived importance given to pica varies depending upon its manifestations. What the individual eats, how often and how focused they are on achieving this are some of the factors that need to be considered when looking at consequences. Chronic pica can lead to problems such as poisoning (e.g. with lead) and vitamin or mineral deficiencies. Ingestion of items such as faeces can lead to parasite infestation whereas dangerous items such as bits of metal or glass may lead to internal injury or organ rupture. Frequency of ingestion is important as regular consumption of an item such as hair, may lead to a blockage requiring surgical removal, whereas infrequent ingestion of the same item may have no consequences. Although consequences may not be immediate or visible, the cumulative effect may still be problematic, and therefore must always be considered. In Amy's case, we do not know whether her pica has any effect on her problematic digestive system, as she has needed an enema and regularly suffers from severe constipation.

Apart from health consequences, pica may also affect the individual's social life by limiting community opportunities due to the greater risk of eating inedibles and preventing the resulting challenging behaviour. Ingestion of certain items can also lead to further social isolation due to the item being consumed, e.g. faeces. This may lead to staff avoiding the individual due to their 'disgusting habits' and, in severe cases, in case of cross-infection due to the increased possibility of parasitic infection.

Treatment/Management

Health reasons should be ruled out first, for example through blood tests, as this removes the need to adapt the individual's life routine and put them through any unnecessary changes. Excluding nutritional supplements, pica is not treated pharmacologically unless it is seen as part of another disorder, for example, obsessive-compulsive disorder. As mentioned above, it is vital to seek advice from a qualified professional. This is especially important when supplementing the diets of people with communication difficulties who are less able to communicate any changes in how they are feeling. This may mean health problems can only be dealt with once the condition has manifested itself and this delay may have a serious impact on the person's health.

Although several studies including Tewari et al (1995) noted that pica is often unnoticed or ignored, in my experience, pica is usually managed through some form of behavioural support programme. Both observations and current government guidelines of practice (Department of Health, 2001) suggest an individual-based approach is necessary if intervention is to be successful as what works for one person is usually not generalisable to others, as is the case in most behaviour support programmes (Piazza et al 2002). The individual's behavioural data needs to be monitored in order to hypothesise needs/causes so that adaptations can be made in order to reduce the need to engage in pica.

Trying to prevent individuals from eating certain plants whilst encouraging them to eat others such as salads at mealtimes can be extremely confusing for an individual with autism and profound learning disabilities as well as being stressful for staff. Limited communication and the fact that this issue may occur on a daily basis may further aggravate the problem. It may also lead to other forms of challenging behaviour such as aggression or self-injury,

which often causes further difficulties for the carer to manage. This can lead to a 'plan-ignore' approach with varying benefits depending upon the desired item as well as the cause of the pica behaviour. Although it may work in the short term, provided the objects ingested are harmless, the effects may be cumulative over the long term or a more dangerous item may be ingested.

In this respect, functional analysis (Mace and Knight 1986) is vital as it provides relevant information regarding the cause of the behaviour and therefore the individual's need. It may help carers to deal with pica once they know why it is occurring and gives them a focus/means on how to support the individual.

Differential reinforcement of incompatible behaviour involves reinforcing the individual for a behaviour that they cannot do at the same time as the problem behaviour. In a study by Dalrow Smith (1987) this was successful in helping a young man with severe disabilities and autism to suppress his pica levels. Incompatible (to pica) tasks included keeping his hands on his work and keeping his mouth empty and a variety of reinforcers were used to reward these behaviours. Asking Amy to carry something (provided it is heavy and large enough to require her to use both her hands, e.g. a laundry basket) has a similar effect as she cannot carry the basket and grasp foliage at the same time. Pilot trials on items that Amy could use when out, such as going shopping, which do not limit her use of the community are currently being looked into.

An enriched environment combining social interaction with alternative activities can lead to a reduction in pica (Mace and Knight 1986). In Amy's case, this can be seen by her reduced pica when enjoying a favourite activity. The amount of response effort involved is relevant in reducing the amount eaten Piazza et al (2002). For example, when a member of staff walks between Amy and the foliage this prevents her from eating the foliage as more effort is needed to by-pass the member of staff. Piazza et al also noted that the quality of the reinforcement was more significant than response effort, showing the importance of person-centred planning.

A literature review by Smith Myles et al (1997) found that no one approach was always successful. They also noted that multiple interventions appeared to be more effective. Thus it should be more effective to reduce Amy's pica in a certain situation by varying more than one factor for example, increasing response effort and providing an incompatible behaviour that can be reinforced, than modifying a single variable.

As with all behaviour support programmes, it is important that planning does not end once the programme starts but is continually adjusted to suit the individual's changing needs. Even perfectly suited reinforcers will not necessarily work at optimal level forever, resulting in the need for regular preference assessments as well as the use of several items over the same time period in order to prevent the person becoming bored. In Amy's case, playing fast music all the time would soon reduce its reinforcement value, hence the importance of seeking other avenues. So far exploring different textures has proved fairly successful. There is also a need for constant lifelong supervision/monitoring of her behaviour in order to prevent any of the consequences already mentioned. This must be carried out even when the behaviour seems to have faded away due to the potential severity of consequences.

A simplified diagram stating methods of preventing or reducing Amy's pica was produced to help staff (see below). This includes a variety of behavioural strategies aimed at supporting staff to be proactive in supporting Amy.

Health management and promotion

Discussions with several health professionals including the local GP provided little external help. The general consensus from those with knowledge of pica was that unless life-threatening, nothing could be done bar monitoring the individual, although behavioural support within the organization was vaguely referred to. Discussions with other staff also revealed that many health professionals such as GPs (normally the first port of call) have no knowledge about this sort of condition due to their limited training in this area. This implies that many worried carers might be dealing with this sort of situation without any help at all. This limited knowledge/training is well documented and a report by Mencap (Singh 1997) noted that over 70% of GPs questioned would like more information and training on learning disabilities. As well as recommending compulsory training for GPs in learning disability the report also confirmed the need for more information to be available to carers and relevant professionals. The report also found that GPs had limited knowledge of the specialist services available to people with intellectual disabilities and were therefore neither using these services nor referring carers to them.

Due to the widely differing needs of each individual, health education is best met by those who know the individual best. In Amy's case this is the staff that support her on a daily basis and have already built up a trusting relationship

with her. Currently we are working towards supporting Amy to choose a healthier lifestyle by not eating as many inedibles and to communicate her needs appropriately by using photographs in a similar way to the Picture Exchange Communication System (PECS) (Bondy and Frost 1994) thus reducing her dependency upon others. Staff are monitoring Amy's fluid intake and exercise levels alongside her diet to optimize her health on a regular basis.

Conclusion

This case study of Amy emphasizes the need for a person centred approach (Sanderson 2000) based on functional analysis in order to meet the individual's needs ethically, without unnecessarily reducing quality of life. I found information hard to come by, and hope that this paper will augment and raise the issue of pica by its publication.

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Guidelines On Preventing/Reducing Amy's Pica

Community

Amy needs supervision at all times.
Distract her when walking near rubbish e.g. pointing out other things to look at.
Walk between her and items she might try to eat where possible.
If the group needs to stop, ensure you wait in a 'clean' area.
Amy often finds it easier to walk back to rejoin the group rather than to stand and wait for them to catch up.

Environment/Safety

Always ensure all unnecessary items especially little ones are locked away
When using cleaning products, keep them within eyesight at all times
All hazardous products must be stored in a locked cupboard.
See company H & S policies/COSHH regulations (H & S Executive, 1999)

Foliage/Shrubbery

Always walk between Amy and shrubbery as this keeps it out of arms reach
Give Amy something to carry (needs to be something that requires both of her hands)
Prevent Amy from eating all plants/fungi to avoid mistakes. If unavoidable & unsure refer to Manager/poisonous plants book.
Inform management if any suspicious plants/fungi are located within the grounds

College

Ensure all materials used are non-toxic.
Ensure Amy is always supervised when carrying out an activity
Only necessary equipment/materials should be left out.
All equipment etc is to be locked up at the end of each session unless safe.

Communication

Use photo/Makaton signing with Amy at all times.
Offer her choices (see toilet) using photos or objects to ensure understanding of options
Teach Amy the Makaton sign for drink and food

Amy

Health/Monitoring

If you suspect Amy has swallowed something that is potentially harmful to her health, inform manager/first aider immediately. If necessary, call an ambulance.
If no immediate action is taken, continue to monitor Amy closely and inform staff on handover. Alert senior on duty if unsure of condition as swallowing something minor may still have harmful consequences.

Reinforcers/rewards

Praise Amy where possible.
Use favourite activities e.g. music or healthy snacks if appropriate

Toilet

Amy needs to be monitored in the toilet to prevent her drinking the toilet water.
Offer Amy a choice of photos (toilet or drink) before going to the toilet.
Offering Amy a drink before going to the toilet prevents her from needing to drink the toilet water

In general

Vary the items on offer to Amy regularly to prevent her getting bored and having to find her own items
Do not reprimand Amy if she exhibits pica – remove item and redirect to activity/alternative.
Ensure Amy is occupied at all times especially low-key sessions - use favourite videos/fast music or sensory play to stimulate her

Time alone

Ensure all unnecessary items are locked away
Ensure all cupboards are locked.
Ensure items left out (e.g. play/sensory) are unbreakable/suitable for use.
Monitor Amy frequently to ensure she does not need the toilet etc

Diet

Monitor/record Amy's food intake
Offer appropriate food if she has missed a meal.
Ensure Amy sticks to her diet to ensure a nutritious balance is achieved

Please use this information in conjunction with other behavioural guidelines and information.

report back

ENVIRONMENTAL WEALTH –USING THE ENVIRONMENT TO PROMOTE TEACHING AND LEARNING

Conference held on 18 June 2003 at the University of Birmingham School of Education

Over 120 professionals from schools, services and further education establishments attended this national conference, the fifth in a series exploring issues relevant to the educational needs of children with multiple disabilities and sensory impairment, and organised by staff from the School of Education working in the fields of learning difficulties and sensory needs.

In introducing the conference, Mike McLinden and Jill Porter explained the choice of title for the day, with the term 'wealth' being used to highlight the potential to be found within the learning environment. They noted that terms 'teaching' and 'learning' are closely linked in educational terminology and are frequently used interchangeably. A key focus of the day therefore was to make a clear distinction between these terms, and in particular raise the profile of the *learning* environment for children and young people with multiple disabilities, exploring how the environment can be harnessed to promote, rather than restrain or inhibit learning. They then outlined different features which can be considered when examining learning environments for learners with sensory needs, drawing attention in particular to the physical environment (for example, furniture, buildings and equipment), the curriculum environment (for example, timetables, learning goals), and the social environment (the people who inhabit the same space as the learner).

The first speaker, Jean Ware from University of Cardiff, described early learning experiences, particularly focusing on the issue of contingency awareness, that is, the learner's understanding that they had affected something. She discussed the earliest levels of sensory awareness and development, including those of vibration, warmth and movement, and how these could be harnessed to help a child to learn. Her discussion included some interesting video clips in which children's obvious pleasure in affecting their environment was clearly demonstrated.

Olga Miller and Jill Porter, from the University of Birmingham, then presented a summary of their recent research investigating the use of multi-sensory environments with learners who have special educational needs. They noted that while a great deal of money has been spent on equipment and spaces for these rooms, there is little documented research to support their use in meeting educational goals. A video showed how a typical child responds to and begins to explore the world around, stimulated by vision and hearing. The learner with sensory impairment may be motivated by the specialist equipment in a sensory room to learn to explore in this way. However, Jill and Olga also showed how naturally occurring environments could also be used to stimulate the senses. These opportunities must also be exploited.

Tony Best, Chief Executive from Sense, then spoke about adaptations that can be made to the environment for learners with sensory needs. He focused on the challenges which learners have in communication, mobility and access to information, considering how communication could be adapted by regulation of information coming to the learner, contingent feedback by a competent communication partner, and by the development of shared attention. He highlighted the particular difficulties learners with sensory impairment can have in understanding spaces, and how our various senses (for example our 'sense' of body space or proprioception) can be exploited to develop this. Tony then examined both the *structure* of the learning environment as well the learning *activity*, to determine how these could be adapted to support learning. Throughout his session, Tony highlighted three key features (*people, time and place*) which need to be considered when adapting a learning environment, and provided examples of the different ways in which these could be used to optimise learning.

Although no conference proceedings are planned for this year, further information about the day can be obtained by contacting one of the conference organisers.

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

Learning Disability Organisations Join Forces

In July it was announced that The Foundation for People with Learning Disabilities had signed an in-principle agreement enabling the staff of the Learning Disability Programme at King's College London (formerly the Community Care Development Centre) to be transferred to the organization.

The move will bring together two of the most respected organisations in the field. The foundation for People with Learning Disabilities has an established reputation for research, policy and horizon-scanning development work. The Learning Disability Programme is well-known for applied work, research and service development.

The move is designed to build on the strengths of both organizations, which share the same values and ethos, and have complementary aims and objectives.

Dr. Andrew Mc Culloch, Chief Executive of the Foundation for People with Learning Disabilities said: "This transfer is a reason to celebrate. We're excited about the possibilities it brings, to increase the range, impact and reach of the Foundation for People with Learning Disabilities' work."

"The sector needs much support to introduce better policies and practice, to improve outcomes for people with learning disabilities and their families, to improve services, to increase opportunities and address the huge social inequalities they face."

Learning Disability Programme staff, including co-Directors Barbara McIntosh and Alison Giraud-Saunders, are due to join the foundation on 31st October this year. The aim is to achieve full integration between Programme staff and the Foundation for People with Learning Disabilities, which will be led by existing head, Hazel Morgan, together with McIntosh and Giraud-Saunders."

For further information contact:

Celia Richardson/William Little

The Foundation for People with Learning Disabilities

Tel: 020 7 802 0312/0313 or, our of hours 07721 587643

E-mail: crichardson@mhf.org.uk or [wllittle@mhf.org.uk](mailto:wlittle@mhf.org.uk)

Special Issue of BILD Learning Disability Bulletin focuses on Profound Learning Disabilities

BILD Learning Disability Bulletin, published quarterly, brings together reprints of recent key journal articles focusing on a topic of particular interest, together with a guest editorial from an expert in the field. It is widely used by a range of professionals as a way of keeping up to date.

In the October issue, the Bulletin will look at severe and profound learning disabilities for the first time since 1997.

For information and subscription details contact BILD on
01562 723010 or e-mail m.davies@bild.org.uk

ACTION for LEISURE

In April Judy Denziloe, Director of Action for Leisure wrote to all subscribers as follows:

As you know, Action for Leisure was funded for three years by a grant from the Community Fund, which ended earlier this year. We have not been able to put in place the funding needed to carry on all of the services and we have had to close the resource centre and put all the resources into storage. We are very grateful to Warwickshire College for offering to store all the resources, free of charge, until we are able to open a resource centre again in the West Midlands.

...I am working from my home office, continuing the services listed below and the fundraising. In view of the lack of staff and storage space, the Trustees have reluctantly decided that Action for Leisure cannot supply the range of play and sensory materials until we are in a position to expand our services again.

Action for Leisure continues to offer:

- Information and advice on play and leisure for disabled people of all ages.
- A range of publications and posters.
- Training on play and leisure for disabled people.

Publication of *Update* will continue, and subscribers to Action for Leisure will still get discount on publications and training fees.

Action for Leisure can be contacted at:

PO Box 9
West Molesey
KT8 1WT

Tel: 0208 783 0173
e-mail: enquiries@actionforleisure.org.uk
www.actionforleisure.org.uk

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

Access to Science: Curriculum Planning and practical activities for pupils with learning difficulties

Claire Marvin and Chris Stokoe

Published by David Fulton Publishers 2003

ISBN: 1-8536-917-3

This book is an excellent resource for ideas, materials and planning for the teaching of science across all the Key Stages of the National Curriculum. The format is very easy to follow and it is the sort of book that you do not have to read from cover to cover. It is very easy to dip into the appropriate section and find useful vignettes of good practice, planning suggestions and worksheets for pupils to use.

The first section of the book sets the teaching of science for pupils with learning difficulties very much within the context of the current curriculum guidelines from the DFES and QCA. It clearly defines the importance of the teaching of Key Skills and how science can be used as a vehicle to support and practise these skills. The book suggests very strongly that science should not be taught as an isolated subject and provides lots of ideas to show how

science can be taught in a cross-curricular way with many references to other publications and materials to support the teacher in their planning.

The needs of pupils from Levels P1 up to P8 and beyond are addressed. The work of Byers and Rose (Planning the Curriculum for pupils with Special Needs) is clearly evident through the authors' use of the Foundation, Access and Extension approach in their planning sections. The planning documents are very easy to follow and offer ideas for appropriate learning outcomes, activities, assessment prompts and easily accessible resources. The planning is divided into a section for each Key Stage and the activities and resources are made age appropriate throughout.

Overall this is a very useful book that provides ideas that tackles planning from the viewpoint of both the subject leader and class teacher and offers interesting and innovative ideas for both the specialist and non-specialist science teachers.

June Green
Deputy Headteacher
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Derbyshire.

BOOKS AND ARTICLES

Access to Science: Curriculum Planning and Practical Activities for Pupils with Learning Difficulties written by Claire Marvin and Chris Stokoe. Published by David Fulton Publishers 2003. This book is reviewed in this issue.

Strategies to Promote Inclusive Practice edited by Christina Tilstone and Richard Rose, published by Routledge Falmer.

My Right to Play: A child with complex needs written by Robert Orr, published by Open University Press 2003.

Making Things Happen: First Annual Report of the Learning Disability Task Force. A comprehensive report on the activities of the Task Force with opportunity to respond. Available from: Learning Disability Task Force, 548 Wellington House, 133-155 Waterloo Road, London SE1 8UG
e-mail: Learning-Disability-Taskforce@doh.gse.gov.uk

Care and treatment? Supporting children with complex needs in healthcare settings. A report of a study into children and young people who spend long periods in healthcare settings written by K. Stalker et al (Joseph Rowntree foundation) published by Pavilion Publishing 2003 ISBN 1 84196 054 3

Children with complex support needs in healthcare settings for long periods.
Summary of the full report by Stalker et al above. Joseph Rowntree 'Findings' series.
Tel: 01904 615905 or www.jrf.org

Come on In! Developing Inclusive play and leisure services report produced by Action for Leisure and Contact a Family West Midlands. Available from Contact a Family West Midlands, Somerville House, 20-22 Harborne road, Edgbaston, Birmingham B15 3AA

Which Way? a guide for parents of children with multiple disabilities produced by RNIB and available from RNIB Customer Services: Tel: 0845 702 3153

Creating a Responsive Environment for People with Profound and Multiple Learning Difficulties (2nd edn.) written by Jean Ware, published by David Fulton Publishers 2003

Direct payments for young disabled people. A report from the Joseph Rowntree Foundation providing a summary of a research project by the Norah Fry Research Centre into direct payments to 16 and 17 year old young people. Tel: 01904 615905 or www.jrf.org.uk

A Parent's Guide to Direct Payments published by the Department of Health. This booklet explains what a direct payment is and how it can be used, and the procedures for organizing a service. Available from the Department of Health, PO Box 777, London SE1 6HX. Tel: 08701 555455

ARTICLES

Lyons, G. 'Go Ahead ... Make my day!' in *SLD Experience* 36, 22-26 Summer 2003
Research into life satisfaction for children with profound and multiple learning disabilities.

Ware, J. 'Eliciting the views of pupils with profound and multiple learning disabilities: is it possible?' in *SLD Experience* 36 7-11 Summer 2003

Lucy Naish 'Exploring Access' in *Eye Contact* Summer 2003. A new information pack which highlights the importance of the physical and sensory school environment.

Richard Walter 'Technology for children with complex needs' in *Eye Contact* Summer 2003.

JOURNALS

Eye Contact – RNIB Education and Employment, 105 Judd Street, London WC1H 9NE.
Tel: 020 7388 1266

Current Awareness Service - up to date materials and information about everything new in learning disabilities.
CAS Subscriptions, BILD, Campion House, Green Street, Kidderminster, Worcs DY10 1JL

Living Well – Pavilion Publishing. Promoting inclusive lifestyles with people who have learning difficulties.

New Opportunity – the newsletter of the Handsel Trust. Tel: 0121 373 2747

BILD Advocacy Newsletter – information about advocacy produced by the Advocacy team. Tel: 01562 723027 or e-mail j.badger@bild.org.uk

BILD Learning Disability Bulletin quarterly reprints of recent key journal articles on a topic of particular interest, with guest editorial from an expert in the field.
Subscription details from BILD on 01562 723010 or e-mail at: m.davies@bild.org.uk

In Contact – the Newsletter of Contact a Family West Midlands. Tel: 0121 455 0655

Foundation Stones – Newsletter of the Foundation for People with Learning Disabilities. Tel: 020 7802 0300 e-mail fpld@fpld.org.uk

SLD Experience – Published by BILD for professionals, parents and those working to support children and young people with severe and profound learning difficulties.
Tel: 01562 723010

Focus - a twice yearly newsletter, produced by RNIB Multiple Disability Service, for staff working with adults who have visual and learning disabilities. It is targeted at 'hands on' workers. 020 8 348 3533

RESOURCES available from the RNIB

Focus is a newsletter, produced by RNIB Multiple Disability Service, for staff working with adults who have visual and learning disabilities. It is targeted at 'hands on' workers.

Each edition of Focus contains articles and information, which RNIB hopes will be of interest to staff, advocates and family carers.

Focus is published twice a year – in the spring and autumn. An annual subscription costs £7 for UK, £8.00 for Europe and £11.00 world-wide. It is available in large print, braille or on tape or disk.

If you would like to receive a free sample edition of Focus, please contact Gill Levy:

RNIB Multiple Disability Service
Falcon Park
Neasden Lane
London NW10 1TB
Telephone 020 8348 3533

RNIB's Multiple Disability Service has a number of products available for customers including leaflets and training resources. Products can be made available in varying formats including large print, tape, Braille or disk. An order form can be found at the end of this leaflet.

Focus Factsheets — information for people involved with adults with visual and learning disabilities

Access to eye care for adults with learning difficulties
Looking for eye problems in people with learning difficulties
How to get the best out of sight testing of adults with learning disabilities and/or no obvious means of communication
Questions to ask the optometrist after the eye test of an adult with learning difficulties or who has no obvious means of communication
Glasses for adults with severe learning difficulties
Minimising problems in eye surgery for adults with severe learning difficulties
Low vision services for people with learning difficulties
Eye drops for adults with learning difficulties
Making sense of prescriptions for spectacles
Keratoconus in people with learning difficulties
Sight in one eye only (monocular vision) and people with learning disabilities
The role of rehabilitation workers for visually impaired people
Understanding and using sight — issues for work with people with severe disabilities
Challenging behaviour in people with visual and learning disabilities
Stereotypical behaviour in people with visual and learning disabilities
Encouraging and developing early communication skills in adults with multiple disabilities
Planning individual leisure activities for adults with visual and learning disabilities — revised version 2002
Hints on teaching skills to people with visual and learning disabilities – revised version
Guiding blind people who are wheelchair users – revised version
Improving environments for people with visual and learning disabilities – revised version
People with Down's syndrome and their eyes

People with Downs Syndrome and their ears
Factsheets on hearing issues for people with learning disabilities
Looking for hearing problems in people with learning difficulties
Making the most of a hearing and ENT assessment for adults with learning disabilities
The effects of hearing problems for people with learning disabilities
Ways to help a learning disabled person with a hearing problem
Hearing aids and environmental equipment for people with a learning disability
Getting your ears tested (a picture booklet for people with learning difficulties).

Factsheets on issues for people with sight problems and other disabilities
Obtaining services for visually impaired people with additional needs
Dementia and sight loss in older people
Improving environments for people with dementia and sight loss

Illustrated and taped booklets on eye care for adults with learning difficulties

Getting your eyes tested (£1) PR11143 print.

Getting new glasses (£1) PR11146 print.

- **Having a cataract operation** (£1) PR11732.

Customers ordering the booklets can also receive the tape to support the booklets. Alternatively, booklets and tapes can be ordered separately.

Directory of eye care

RNIB has produced a Directory of optometrists and orthoptists willing to test adults with learning difficulties and/or limited communication skills. The full directory costs £25 and is available from RNIB at Customer services. Regional directories cost £5 and are available from RNIB Multiple Disability Service.

Right to sight resource pack and video for staff working with adults with learning difficulties

This pack has been produced to show staff what can be done to help adults with learning difficulties gain access to eye care. The pack costs £89.00. To order your copy please contact RNIB Customer services quoting reference PR11142. Braille, tape and disk formats are available from RNIB Multiple Disability Service.

Sight Matters

Sight Matters is a short video about eye tests for adults with learning difficulties. The video features three people with learning difficulties talking about their experience of visiting the opticians. The video shows them booking in at reception, sitting in the optician's waiting room, and having an eye test. There is also a section on choosing new glasses. The people involved in the video stress why it is important to have regular eye health checks.

The video is also available signed in British Sign Language (BSL) and is accompanied by the free illustrated booklets and tapes: Getting your eyes tested and Getting new glasses. The video costs £20.00, and is available from RNIB. When ordering, please quote PR11573 for the BSL version and PR11574 for the ordinary version.

Orders for leaflets **with PR numbers**, or orders for tape, braille or disk, the Right to Sight pack, or Sight Matters, should be sent to: RNIB, Customer Services, PO Box 173, Peterborough, PE2 6WS

Telephone: **0845 702 3153** for the price of a local call, quoting the leaflet PR number.

Cheques should be made payable to **RNIB**, and should be marked RNIB income code **2525.8127.00**.

Alternatively.....The majority of the leaflets are now available on the Internet:
www.rnib.org.uk/multidis

COURSES AND CONFERENCES

SEPTEMBER

24th An Introduction to Person Centred Planning
Organised by: Sunfield Professional Development Centre
Led by: Mandy Neville
Venue: Sunfield, Clent
Further details: Sunfield PDC
Tel: 01562 883183
e-mail: sunfield@sunfield.worcs.sch.uk

24th to 26th BILD Annual Conference
Valuing Health: health care to match health needs
Organised by: BILD
Further details: Miriam Caldwell
Tel: 01562 723025
e-mail: m.caldwell@bild.org.uk

26th Intensive Interaction
Organised by: Sunfield Professional Development Centre
Led by: Dave Hewett
Venue: Sunfield, Clent
Further details: Sunfield PDC
Tel: 01562 883183
e-mail: sunfield@sunfield.worcs.sch.uk

OCTOBER

10th Sherborne Developmental Movement – Level 1
Organised by: Sunfield Professional Development Centre
Led by: Cyndi Hill and George Hill
Venue: Sunfield, Clent
Further details: Sunfield PDC
Tel: 01562 883183
e-mail: sunfield@sunfield.worcs.sch.uk

15th Developing Life Stories and Person Centred Planning for People with Profound and Multiple Learning Difficulties
Organised by: BILD
Venue: Nottingham
Further details: Mark Gray
Tel: 01509 631 230

15th Understanding the genetic causes of learning disability: how knowledge can guide good education and social practice
Organised by: Royal Society of Medicine
Venue: University of Dundee
Further details: Rachel Beresford-Pierce
Tel: 0207 290 3934
e-mail: learning.disability@rsm.ac.uk

16th Meeting the Needs of People with Profound Learning Disabilities
Organised by: BILD
Venue: London
Further details: Miriam Caldwell
Tel: 01562 723025
e-mail: m.caldwell@bild.org.uk

22nd Making Advocacy Accessible
To explore ways of making advocacy more accessible to those with significant barriers to communication and complex needs.
Organised by: BILD
Venue: Kidderminster
Further details: Miriam Caldwell
Tel: 01562 723025
e-mail: m.caldwell@bild.org.uk

30TH NASEN/TES Special Needs Exhibition 2003
to Programme of seminars and NASEN/TES Book Awards.
1st Nov Venue: Business Design Centre, Islington, London

NOVEMBER

5th Advocacy
Organised by: BILD
Further details: Miriam Caldwell
Tel: 01562 723025
e-mail: m.caldwell@bild.org.uk

6th Life Story Work
Organised by: BILD
Venue: Kidderminster
Further details: Miriam Caldwell
Tel: 01562 723025
e-mail: m.caldwell@bild.org.uk

11th Meeting the Needs of People with Profound Learning Disabilities
Organised by: BILD
Venue: London
Further details: Miriam Caldwell
Tel: 01562 723025
e-mail: m.caldwell@bild.org.uk

12th Life Story Work
Organised by: BILD
Venue: Kidderminster
Further details: Miriam Caldwell
Tel: 01562 723025
e-mail: m.caldwell@bild.org.uk

12th Developing Life Stories and Person Centred Planning for People with Profound and Multiple Learning Difficulties
Organised by: BILD
Venue: London
Further details: Mark Gray
Tel: 01509 631 230

13th Education and Leisure for Teenagers and Young Adults with Profound Disability
Two day training conference.
Organised by: Catalyst Education
Venue: Queen Alexandra College, Birmingham
Further details: Tel: 0845 127 5281

17th Making Advocacy Accessible
To explore ways of making advocacy more accessible to those with significant barriers to communication and complex needs.
Organised by: BILD
Venue: London 36
Further details: Miriam Caldwell
Tel: 01562 723025

'Supporters Club'

The last in a series of family training days for grandparents, adult siblings, aunts, uncles, friends and neighbours. A chance to meet together and discuss common issues.

Organised by: Sunfield Professional Development Centre
Venue: Sunfield PDC, Clent
Further details: Sunfield Professional Development Centre
Tel: 01562 883183
e-mail: sunfield@sunfield.worcs.sch.uk

20th Valuing good practice for children and young people with severe and profound and multiple learning difficulties

Organised by: BILD
Venue: East Midlands Conference Centre, Nottingham

Further details: Miriam Caldwell
Tel: 01562 723025
e-mail: m.caldwell@bild.org.uk

DECEMBER

4th Life Story Work

Organised by: BILD
Venue: London
Further details: Miriam Caldwell
Tel: 01562 723025
e-mail: m.caldwell@bild.org.uk

17TH Developing Life Stories and Person Centred Planning for People with Profound and Multiple Learning Difficulties

Organised by: BILD
Venue: Leeds
Further details: Mark Gray
Tel: 01509 631 230

2004

JANUARY

14TH Developing Life Stories and Person Centred Planning for People with Profound and Multiple Learning Difficulties

Organised by: BILD
Venue: Liverpool
Further details: Mark Gray
Tel: 01509 631 230

FEBRUARY

18TH Developing Life Stories and Person Centred Planning for People with Profound and Multiple Learning Difficulties

Organised by: BILD
Venue: Birmingham
Further details: Mark Gray
Tel: 01509 631 230

MARCH

17TH Developing Life Stories and Person Centred Planning for People with Profound and Multiple Learning Difficulties

Organised by: BILD 37
Venue: Brighton
Further details: Mark Gray
Tel: 01509 631 230

JULY

7th to 10th Transform 2004 – The New Assistive Technology Conference and Exhibition
World Conference to explore the latest developments in assistive technology.
Keynote speaker: Christopher Reeves
Venue: University of Manchester Institute of Science and Technology
Further details: Alison Littlewood
Tel: 01457 819790
e-mail: alison.littlewood@atandi.org

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: Tel: 0121 414 4866

M.Sc/PG Diploma in Learning Disability Studies

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

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

Further details: Helen Bradley, course director

Tel: 0121 415 8118

Profound Learning Disability and Multi Sensory Impairments

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

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

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: JTI Office@man.ac.uk

website: www.education.man.ac.uk/pmld/

Certificate in Working with People who have Learning Disabilities

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

Wide range of units available for study. Each student is supported by a tutor throughout the course.

Further details: BILD Learning Services

Tel. 01562 723010

Certificate in Working with People who have Learning Disabilities: your pathway to achievement

The Learning Disabilities Award Framework route to qualification for staff supporting people with learning disabilities. A course programme and supporting materials, including a trainer's toolkit and student workbook.

Available from Pavilion Publishing Tel: 01273 623222 or e-mail: info@pavpub.com

PMLD-Link

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