

# PMILD LINK

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

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

You may have noticed already that this issue is not only bigger than usual, but is also in smaller print. The theme of *transition* has attracted more than the usual number of articles, and there are also a number on other topics as well. We hope that this will make the increase in subscriptions (see below) easier to bear!

The scene is set by Martin Routledge's report on the research carried out by the North West Training and Development Team, and many of the issues raised are developed in the articles following it. It is good to have a mix of contributors from a wide range of statutory and voluntary services, parents and users from all parts of the country - as well as a parent writing from Argentina. This ensures that we have a wide range of perspectives, from the personal to the service providers, and this helps to give an all round picture of the intricacies of transition. As always, very many thanks to everyone who has taken time to write for this issue. If any readers are inspired to follow on this theme for the next issue, we would be very pleased to have more articles on the same topic.

A large number of issues around transition have been raised at the two events summarised in *report back*, and many of these have been reflected in the articles: collaboration between services; age appropriateness; involving parents/carers and service users in decisions; the nature of post school provision and supported employment opportunities.

Many readers will be familiar with 'Bag Books', but few, if any will have read the Fulham and Hammersmith Chronicle (July 8th 2000) reporting on the supported employment of two trainees with profound learning disabilities in the Bag Books workshop. Congratulations to Chris Fuller for showing that this is, indeed, possible.

Loretto Lambe introduces the next theme - *Health Issues*. As she points out, the issues are many and various and we hope that this is something that many of you will want to write about. The topics she mentions are often of great concern to parents, carers and practitioners, so share your experiences with other readers, and ask for help and comments too if you like. But don't forget that we are keen to have articles on any subject, not only on matters relating to health.

## **BUSINESS MATTERS**

### ***Subscriptions***

As this is the last issue of the 1999/2000 subscription year it is time once again to renew your subscription. As mentioned in the last issue, we have reluctantly had to increase the rates to take account of rising costs, and the costs of moving into the world of technology. For the first time, we have different rates for individual subscribers and organisations. This is to try to keep down the costs for those subscribers who pay for their copy out of their own hard earned money, as opposed to those who can persuade their place of work to subscribe. We hope that this will mean that we will not have to raise subscriptions again too soon.

A separate form is enclosed with this issue, and we hope that you will think that £10 for an individual and £15 for an organisation is still good value. Those readers who have already sent a subscription for £10 (or £15) can rest assured that they are already paid up for the coming year.

### ***Articles***

Articles or any other material for the next issue should reach me by the middle of January 2001. They can be sent by post or by e-mail (Rich Format Text please, or I can't access it) to the following address:

**Carol Ouvry, PMLD-Link** The Old Rectory, Hope Mansell, Ross-on-Wye, Herefordshire HR9 5TL  
Tel: 01989 750382 e-mail: PMLD@mansell.wyenet.co.uk

# COULD DO BETTER - transition from school to adulthood for young people with "complex needs"

## Introduction

The North West Training and Development Team is a small team of advisors funded by health authorities and social service departments in the north west region. The mission of the team is to support the full inclusion of people with learning disabilities in society. For about five years now the NWTDT has undertaken work relating to the transition of young people from childhood to adulthood. This has included consultancy to service agencies, support for parents groups, the co-ordination of a regional interest network, and the publication of guidance (Routledge 1998). This article relates experience from the author's own experience and that of colleagues as well as from published material.

Research and practice guidance on transition has been published by a range of agencies (Flynn and Hirst 1992, Further Education Unit 1994, Social Services Inspectorate 1995a and 1995b, Pearson et al 1999, Ryan 1997, Routledge 1998). Authors have highlighted fragmentation of policy, of agency and professional roles and underdevelopment of appropriate and effective practice in this area of work (Routledge, 1998, Morris 1999a).

## Issues

It is clear that the transition period can often be very challenging for young people and their families. Without effective support this can be a time of confusion and dislocation. There are also fears about the availability and adequacy of supports and services in adulthood.

It has been noted that:

*"A large number of different agencies and professionals contribute to individual transitions, often in a fragmented and uncoordinated way. There is no certainty that their contributions will be consistent and compatible. It is impossible for a single department or agency to help an individual to achieve all the goals of transition." (Russell 1993)*

This statement was made prior to the implementation of the Special Educational Needs Code of Practice (DfEE 1994), with its important transition related elements. Unfortunately, however, many people are still not benefiting from effectively co-ordinated transition support. Professionals, managers, parents and young people very frequently report that their experience of transition planning is one where the main agencies and professionals do not link sufficiently effectively. We appear still to have a situation where, in the main, the separate agencies, sub parts of agencies and professional groups are focused upon their own imperatives and where coherence is too often the exception rather than the rule.

Local implementation of the Code of Practice appears to be variable. Even when LEAs operate the Code well, there is no guarantee of effective involvement from other agencies - careers, children's and adult social services, children's and adult health purchasers and providers etc. These agencies are not under sufficiently effective requirement to participate fully.

It appears that local factors such as service resources, local policy, organisation and agency cultures and individual professional interest/availability are strong determinants of defacto transition support arrangements.

There is increasing concern about support for people with learning disabilities and "complex needs" as they leave school and move into adulthood. Though demographic information relating to people with learning disabilities is not entirely satisfactory, there does seem to be some evidence that the numbers of people with greater disabilities and complex health care needs coming through into adulthood is increasing. Anecdotal evidence from districts linked to the North West Training and Development Team certainly confirms this.

As the anticipated number of young people with complex needs increases so do concerns about the ability of service agencies to properly provide for them. Recent research confirms that these are appropriate fears (Pearson et al 1999, Cohen et al 1998, Morris 19991)).

These concerns are increasingly being reflected in government guidance and emerging policy. It is notable that two of the five sub groups contributing to the development of the National Learning Disabilities Strategy focus upon children and health. Within the children's sub group the issue of transition is highlighted for consideration. The "Signposts for Success" guidance (DOH 1998) stress the importance of

improved linkage between specialist and primary and acute care professionals in order to address the health inequalities faced by people with learning disabilities.

In brief, some typical concerns are around:

- Effective, timely and coherent assessment and planning in the later school years, at the point of transfer to adult services and "after transition"

Systems for assessment are often not co-ordinated across agencies or parts of agencies. Information on needs may not be transferred appropriately, either for individuals or on populations for planning purposes. Parents often describe feeling as if they are starting again with adult services and professionals as their son or daughter leaves school, as if all the years at school had not happened

- Dislocation of health provision in transition

Cohen et al 1998, reporting a major survey in two London districts noted, for example:

*"There were a number of problems with hospital transitions, usually in relation to outpatient services, where consultants made individual decisions about transferring to the corresponding adult clinic. Hospital transitions particularly affected young people with PM LDs who often attended several different clinics. Some carers of these young people were having severe problems with health service transitions generally, although they welcomed a newly introduced healthcare transition plan and/or follow up from a school nurse"*

- Lack of competence and capacity of social care services in providing for people with greater disabilities and significant health care needs and/or lack of health care support for social care services

For many people and their families this is a source of great worry during transition. While a young person has been at school there has often been intervention from a school nurse, and from on-site therapists. As this form of support ceases or reduces there are fears about the competence of adult services to meet needs.

Staff in adult learning disability services often feel that they cannot guarantee to offer appropriate support for people with "complex needs". The situation is very variable, depending, for example, on service history and culture. Sometimes issues can arise, for example, about social care staff preparedness to administer medications or other interventions. In some areas there are problems around local "continuing care" policies or practices, with disagreements around respective agency responsibilities.

This can mean that even people with relatively simple needs might find themselves poorly served. In one example, a young man leaving school who received food through a tube into his stomach had always been assisted by the school nurse. The staff at the day centre he was due to attend expressed their nervousness, having not supported anyone with this need before. The specialist learning disability nursing service stated that they could neither train the social care staff nor support the young man directly as they did not have the necessary knowledge or skills. The local district nursing service stated that people with learning disabilities did not form part of their "core business". Furthermore, they could not train social care staff because of the issue of "vicarious liability". The young man faced the prospect of staying at home with his single parent who was herself very ill! Fortunately in this case good sense prevailed and local protocols between the agencies led to a satisfactory solution.

- Barriers to access to primary care and non-specialist health provision. These are commonly reported and well described in Signposts for Success.

### **Promising possibilities**

Though the author has not come across any districts that have in place what could be considered a comprehensive and fully satisfactory set of transition supports, progress is being made in some areas. Some district agencies have managed to achieve joint policy and procedures, steering groups, joint assessments, better provision of information, smoother links between specific child and adult services.

The National Development Team (Pearson et al 1999) has recently been looking at health care for young people with learning disabilities, aiming to identify issues and concerns, good practice and ways of improving transitional planning.

The NDT project identified examples of developing methods for building knowledge and awareness of the health needs of people with learning disabilities in the Primary Health Care Team and Community Health Services.

- The National Development Team, with others, has developed a personal health record - Advocating for Health Personal Health Record. Copies of this personal booklet have been piloted in some of the localities in the project and elsewhere. The feedback suggests they bridge the gap between the information needs and points of view of young people with learning disabilities, their relatives, professionals and other people who support them.
- A Primary Health Care Co-ordinator working with carers, schools, GPs and several other disciplines, including audiologists and chiropodists to improve services for people with learning disabilities. Achievements include connecting up the voluntary sector and GPs, piloting the use of personal health records and helping primary health care teams identify people with learning disabilities.

*"The work has brought enormous differences in the practice of primary health care teams, particularly because individual professionals have welcomed the possibility of interesting work." (Pearson et al 1999)*

- Learning disability trained health workers working in partnership with general practices to develop appropriate preventative health plans for people in their practice population who have a learning disability.
- A Community Nurse visiting day centres, looking into what health screening people with learning disabilities are receiving, and identifying problems.
- A 'Well Women' initiative included women with learning disabilities and breast screening had been arranged for them

In preparing the NWTDT guide "After School What Next - Developing Multi-Agency Transition Policy and Practice" (1998) the author came across a number of examples of existing and developing practice that seemed likely to improve support for young people and their families in transition Examples include:

- A health transition team spanning the child/adult age range;
- Nursing staff with specific responsibility to co-ordinate health assessments and working directly alongside social workers assessing for social care need;
- Essential lifestyle planning with people with complex support needs;
- Early identification of people with very complex needs with the objective of planning services well in advance;
- Effective and creative approaches to improving communication with people who do not use words.

#### **The future**

At the time of writing, there are many policy developments with potential implications for transition. At this point it is not possible to do more than "crystal ball gaze" about the possible impact of most of these. Some of the key developments are:

***The Learning and Skills Bill*** - The role of the Learning and Skills Councils. To what extent will their membership and priorities reflect the needs of young people with learning and complex difficulties? Proposals to extend transition planning beyond school leaving - to be welcomed but who will manage such planning post school?

***The role of the Youth Support Service and Learning Mentors*** - for all young people of thirteen plus. Will these new advisors have the necessary skills to support young people with complex disabilities in transition?

***The introduction of direct payments for young people and carers*** - will young people with disabilities have personal advisors as under the **Children (Leaving Care) Bill**?

***Implications of the Disability in Education Bill*** - the impact of bringing education within disability discrimination legislation, including school, further, higher and continuing education.

***Quality protects*** - The CDC analysis of QP Management Action Plans (DOH 2000) shows that transition is becoming a higher priority in most areas but there are questions about how much focus there is on the specific needs of people with a learning disability

At the time of writing we have a draft revised Code of Practice out for consultation and are anticipating the publication of the National Learning Disabilities Strategy. In respect of transition the draft Code of Practice focuses heavily on the role of the new Connexions service and reminds agencies of various legal responsibilities. It remains to be seen how the Connexions service will impact. The author's view is that local champions of people with learning disabilities will need to work hard to influence the ways the services are set up and work to ensure that they benefit properly.

In respect of the National Strategy it is encouraging that transition has featured strongly in the consultation seminars and submissions and across several strategy sub groups but it still remains to be seen what will emerge in the final publication and the strength of mechanisms for implementation that are established.

### **Conclusion**

It will remain difficult to achieve major and sustainable improvements in transition support until some of the structural sources of fragmentation of agency effort are removed or undermined. At the time of writing there do seem to be attempts at a national policy level to promote the reduction of some sources of fragmentation. The development of Joint Investment Plans, shifts towards joint or integrated commissioning, opportunities likely to emerge from the potential pooling of budgets - are all ways of breaking down the barriers. At the same time as these potentially helpful policy initiatives however, local agencies will also have to incorporate new players such as the Primary Care Groups/Trusts.

As a final thought, the author would offer the view that if young people and their families are to receive the kind of support in transition that they deserve, local agencies and professionals will have to face whatever system context they find. They will have to take collective responsibility for constructing workable and effective local solutions. In doing this they will also have to take a more proactively partnership approach with families and young people. There are now some promising examples of approaches and improvements. Local professionals and their partners need to learn from these and build their own improvement

### **Martin Routledge**

#### **Co-ordinator, North West Training and Development Team**

The NWTDT can be contacted at Calderstones, Whalley, Lancashire. Tel 01245 821 334

### **Acknowledgement**

Phillipa Russell, Director of the Council for Disabled Children provided useful ideas for this article, especially the sections on developing policy.

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## MOVING ON - 'Getting your act together'

*Moving on from school is never easy, but for people with profound and multiple disabilities it can be even harder. Cathy Heaney told Paul Dumbleton, the PAMIS Glasgow Co-ordinator, about her experiences with her son, Edward.*

Edward is twenty six now and attends a resource centre every day. He was at school from the age of three, and stayed there until after he was nineteen. I remember a meeting at the school when he was younger. A mother of an older lad told us 'youngsters' that we should "get our act together and make sure that there was something for our children to do after school." Her son had left school but was languishing at home all day with nothing to do. Once Edward came up to leaving school I realised that she was right, and had to spend the next few years getting things sorted out.

Edward, of course, had a 'Record of Needs'. When he was fourteen there was a Future Needs meeting, but it was just decided that he would stay on at school. When Edward was nineteen we had a new Social Worker appointed. He contacted me and said that he would take me to see the three day centres that might take Edward. In the car on the way I said that I felt nervous and he replied that he did too, because he knew nothing about learning disability always having worked with young offenders!

After the visits nothing happened again for weeks. Eventually I was invited to a meeting at one of the day centres. When I walked into the room I was overwhelmed by the number of professionals, including the managers of all three centres, who wanted to know what I wanted from a day centre. I had to be very clear that I would not accept a part-time placement. I was worried about the lack of support, for example the school had two nurses while the centres had none.

Edward then left school, with no place ready for him. Eventually one of the centres offered a place - but after only a week they said that it wasn't working out and he was back at home again. It seemed that he had too many needs for the staff to cope with. We felt unwanted and abandoned. Months later and after a great deal of effort, a place was found at another centre. Once again there were delays while cash to pay for a sessional carer to look after Edward was allocated and approved. Eventually Edward started to attend the Centre. Five years later he is still there.

We have been lucky to have the same excellent support worker for five years now. He knows Edward well and we can employ him for extra hours of home support through the 'Independent Living Fund'. Now Edward also gets help at the centre from a Community Service Volunteer (CSV). There have been a succession of young men volunteering from all over Europe - all of them excellent. His current CSV even brought his parents to meet us when they were visiting from Germany.

Just like that older mum years ago, I suggest that younger parents should prepare for the transition from school. Nothing happens automatically. You need to make sure that it happens.

### ***If I did it all again I would:***

- ask more questions - at an earlier stage;
- prepare for meetings - find out what meetings are for and who will be there;
- find out information for myself - and not wait to be told. Professionals sometimes don't tell you and often just don't know;
- keep in touch with other people in similar situations to give and get support.

**Cathy Heaney would be pleased to hear from other parents who need information, advice or support during this difficult stage. She can be contacted via the PAMIS Glasgow Office on 0141 226 4541.**

## TRANSITIONS - NEED IT BE TRAUMATIC?

"This is worse than when I was first given Michael's diagnosis." An extreme response perhaps, but these words were said to me some years ago during a meeting with a group of parents and carers whose children were in their final year at the senior special school in Oldham and when were preparing for the transition into adult services. For some years I had been aware that the transition experience for many, if not most, parents was a source of considerable concern and anxiety, but this particular parent's response was a powerful learning experience for me and one that, in the intervening years, I have never forgotten. Whilst as professionals working with young people who have a learning disability we work with a new group of leavers and their carers every year, we must never forget that for the parents and students themselves this is their unique experience and we must always remain alert to the differing levels of concern and anxiety that can be engendered by such a significant life change for both students and parents.

Young adults with special needs have been moving between children's/education provision to adult services for thirty years, but the recognition in law that this transfer needed to be carefully and consistently managed between various agencies did not materialise until the passage of the *Disable Persons (Services, Consultation and Representation) Act 1986*. Section 5 of the Act requires Local Education Authorities (LEAs) at the Year 9 Review to obtain an opinion from the Social Services Department (SSD) as to whether a child is or is not a disabled person and is therefore likely to need future services as an adult. In addition the LEA is required to notify the SSD eight months before the date when a young person with disabilities is likely to leave full time education and the SSD must carry out a multi-disciplinary assessment within five months of the LEA notification unless the student or carer refuses this.

The 1986 Act was followed by the *Children Act 1989*, the first children act to specifically address the issue of disability with its injunction that services should be provided to minimise the effects of the child's disability and give them opportunities to lead lives that are as "normal as possible" (Schedule 2 Para 9). A primary aim of the Children Act was "to promote access for all children to the same range of services". Thus the concept of inclusivity, so much a plank of the current government's policy was and remains at the heart of the Children Act 1989 (Guidance Volume 6 pp 1-2), and this should always guide our thinking and planning in respect of every student with special needs who makes the transition from school to adult services. The *National Health Service and Community Care Act 1990* (NHSCCA) deals with the service provision to vulnerable adults (18 + years) and was the first piece of legislation to make explicit the circumstances under which local authorities had a duty to assess need. Section 47(1) of the Act details the conditions under which local authorities must assess the needs of disabled and/or vulnerable adults. Young people leaving special education provision clearly fall within this category.

The *Carers (Recognition and Services) Act 1995* gave carers the right to request an assessment of their needs and if they do so the local authority has a duty to carry out such an assessment. Thus the legislation from 1986-1995 gave some coherence and a value base (inclusion and person centredness) to a process which arguably could be said to begin at the Year 9 Review within school and end with the provision of appropriate services or package of services to meet the needs of the young adult and alleviate the anxiety of his/her carer. I think that from our own experience we know that there is frequently a gap between what the legislation says and what actually happens in the lives of human beings and we need to explore what actually happens to students and carers as they come to negotiate this complex and potentially traumatic experience.

My experience within my own local authority suggests that the transitions process over the past decade has become more complex for all concerned as, following the duties laid down by the NHSCCA 90, we have moved from service led to needs led provision. Up to approximately eight years ago the pathways for young people moving into adult services were relatively straight forward and limited; either the student was placed in a large day centre, especially if he/she had higher levels of dependency as a result of multiple and/or complex disabilities, including health care needs, or he she



was placed in an assessment facility for up to a further two years whilst their needs were further assessed.

Over the past decade there have been significant developments within the adult learning disability service (LDS) against the background of seeking less segregated provision and more person centred planning. Opportunities and career paths have been developed within local sector FE colleges, supported employment, independent living skills courses, provision to meet the cultural and religious needs of ethnic minority groups, the creation of satellite groups within local communities in addition to more traditional day centre provision.

Whilst the outcomes for many service user have been creative, stimulating and inclusive and many parents have been thrilled at the achievement of their child attending college or working, in many cases such outcomes have only been realised at the eleventh hour for a variety of reasons, some of which have been beyond the control of the service. Thus the final months at school for some parents and students have remained fraught. Much remains to be done.

When I look back over service developments during the past decade or so my impression is that major and positive changes have occurred to enhance the quality of life of students who have significant cognitive disabilities but who do not have additional needs as a result of challenging behaviour and/or multiple disabilities including those with complex health care needs. In relation to the former, these are the young people who are still most likely to be placed out of borough in "specialist" provision and they are likely to present with behaviours deemed to be within the autistic spectrum whilst the latter remain more likely to be placed in more traditional day centre environments or for those with the most complex health care needs, within a young person's disability unit of a nursing home. These issues must be addressed as it is not acceptable to allow young people who are the most dependent to miss out on some of the exciting developments taking place within the services.

#### Objectives of the Transition Process

1. Smooth, seamless transition of young people with disabilities from children's/education services to adult services/world.
2. Minimise the anxieties engendered by such a significant life change for both students and their carers.
3. Provision of QUALITY services/careers for all young people with disabilities moving from secondary education to adult provision, including those who have more multiple and complex disabilities, health care needs, and challenging behaviour.

I would like to look briefly at each of these objectives in turn, and relate the objective to outcomes within my own local authority.

#### 1. *Smooth Seamless Transition*

Many documents on transitions refer to a 'seamless' process. To my mind it is not possible to make such a watershed in people's lives 'seamless', particularly as most health and social service provision has separate organisational arrangements for the delivery of services to children and adults. What is needed is clear, demonstrable planning of the process, clear publicised information on what will be happening, when, who will be involved and why; what options will be available to young adults with disabilities and carers, and who will be the guide through the maze i.e. a consistent key worker.

No single agency has been given sole responsibility for supporting young people and their families during transition. There are a number of agencies involved in the process, the major players being; local education authorities, health services, social service departments (children's and adult divisions), further education providers, employment providers, and the careers service.

In order to agree and co-ordinate a process and determine responsibilities a multi-agency TRANSITIONS STEERING GROUP (TSG) was formally set up approximately five years ago, involving managerial and professional representation from the main players together with carer representation. Initially the group met bi-monthly but now meets quarterly. The remit of the group is to oversee all the strategic issues involved in developing the transition process in Oldham, monitoring

the current process and troubleshooting issues as they arise. The group is currently chaired by the Team Manager from the adult learning disability service but the possibility of a rotating chair has been mooted and will be pursued. Some examples of the work produced by the group are given below:

#### *Calendar for the Transition Process*

The Calendar charts the transitions process from the Year 9 Review through to the student leaving school, and bearing in mind the overt commitment of the adult learning disability service to working in a person centred way. The subtitle of the document clearly states "Making the Young Person and Carer/s Central to Planning".

The Calendar clarified year by year

WHEN certain actions should take place

WHAT that action should be

BY WHOM and WHO INVOLVED - accountability

WHAT legislation or guidance underpins the above.

Part of the Calendar is appended to this article.

The importance of any process, not least a person centred one, lies not in the words in any protocol or document but in the actual outcomes for young people and their families. Thus parents and carers will be given copies of the Calendar; the children's service social worker who has been allocated to attend all Year 9 Reviews of statemented children together with a colleague from the Careers Service have been given a clear mandate from the TSG to ensure that students and carers are at the centre of the process and that their views are encouraged, heard, and recorded at all times.

#### *Early Referral Protocol*

Section 5 of the Disabled Persons Act 1986 lays certain duties upon LEAs and SSDs in respect of the preparation for the transition from school to adult provision (see above). What we have found in practice is that the timescales laid down in the legislation are far too short to enable appropriate person centred assessments of need to be undertaken. Twelve months, arguably, is a minimum but the core management team in Oldham are trying to initiate assessments in the autumn term of the penultimate year at school. However, it is recognised that in a minority of situations even this timescale does not afford sufficient time to appropriately plan needs led services for those young people who have particularly complex needs.

To address this problem the TSG has produced an EARLY REFERRAL PROTOCOL whereby the adult core management team will accept referrals for joint assessment with colleagues from children's services for students between 15-16 years of age under any one of the following circumstances:

- a) where the student has a diagnosis of autism or exhibits behaviour suggestive of an autistic spectrum disorder;
- b) where the student's behaviour presents a threat to either their place within the family and/or school;
- c) where the student has complex health care needs;
- d) where the student is likely to need alternative accommodation when he/she reaches adulthood (18 years) or upon leaving school.

This time scale should give service providers ample time for planning.

#### *Health Care Needs in Transition*

A recent publication 'Hurling into the Void' highlights a problem faced in transition by young disabled people with "complex health and support needs". The report concludes that "they all require a combination of health and support services in order to access a good quality of life. There is evidence that many of these young people experience a failure of health and social services to meet their needs". Recently the TSG has set up a working sub-group to address issues of health, general and complex, within the transition process. The group comprises the heads of nursing services for both the children with disabilities team and the adult LDS; the head of the speech therapy service; and the team manager Adult LDS. This group will keep health care issues to the forefront of the TSG agenda.

In a further development, by using multi-disciplinary assessments of several young people with complex health care needs and working as a team we have been able to identify very clearly shortfalls

in service provision to this group - eg. in physiotherapy, occupational therapy, community nursing, behavioural nurse specialist, communication therapy. Having costed the additional need arising from specific care plans, a bid has been submitted within the Joint Investment Plan (JIP). We are very optimistic that out of this work will result a health care team dedicated to co-ordinating and addressing all the health issues of young people in transition.

#### *Curriculum Issues - Post 16*

Recent work within the TSG has begun to focus on the post 16 curriculum within the special school and how to make this more relevant in the preparation of students for adulthood, independence, and maximising the quality of life. We are particularly keen to encourage the forging of closer links with various provider services much earlier in the school curriculum rather than relying upon brief 'taster' sessions in a variety of placements during the final school year. Positive relationships are being developed between the special schools and various organisations - the local colleges, the supported employment service, Youth and Community providers. Contacts with students are beginning earlier and plans are beginning to be made at the Year 9 Review. Such a programme would give students more opportunity to have a more in depth experience of potential future provision in the adult world, and if the contacts and experiences are recorded in appropriate ways - audio-visual, photographs, personalised drawings or symbols - the information can be made up into a portfolio to assist students to make as informed a decision as possible when the time comes. This programme will not be only for more able students, we are working to give students with more profound and multiple disabilities access to all these services (see below).

#### *Assessment*

The assessment process adopted by the care management team within the adult LDS follows a lengthy 'getting to know you' process and recognises the centrality of the user and carer. There is a clear and conscious avoidance of the 'professional knows best' attitude notwithstanding the nature and degree of disability. Indeed it is recognised that more time will be needed to 'get to know' a user who has more complex and significant disabilities and it is more likely that those young people will be allocated scarce staff resources to build up Essential Lifestyle Plans, Communication Dictionaries etc. in order that their needs can be as comprehensively understood as possible.

#### *2. Minimise the Anxieties of Transition*

The most effective ways of minimising anxiety are:

- providing users and carers with accurate and current information when they want it and in a format that is meaningful to them;
- providing opportunities to experience potential services;
- giving access to a consistent worker who can support them through the process.

Information available in my own service consists of a booklet in three major languages "After School - What Next" which identifies and briefly describes a whole range of services and contacts for school leavers and their carers; a transition video, also available in the two major ethnic minority languages; and it is hoped to make the Calendar available to families in the near future. We have also attempted to organise parents' groups, including those for parents from ethnic minority backgrounds and for parents of young people with more multiple and complex needs. The Year 9 Review would seem to be an appropriate starting point to begin the information giving process to students and carers but at a pace which they must dictate. At that review a key worker could be identified as a contact person to assist families through the process and at this stage it would be likely to be a worker from children's services or the careers service.

To date I have yet to find a satisfactory way within existing resources of giving families consistently reliable and up to date information as the information written down or on video relatively soon becomes out of date particularly in a rapidly developing service. Having said all this we must acknowledge that until appropriate adult services are established to the satisfaction of both user and carer, anxieties throughout the process will remain, thus the role of a support worker is crucial to the family as a whole.

### 3. *Provision of Quality Services/Careers*

Our aim must be to provide a quality service for all young people with special needs notwithstanding the nature and severity of the disability. What is quality in this context? I'm not sure that it's an absolute concept, often depending upon the perception of users and carers that they get the service or provision that they need or want. From a service perspective quality may be linked to values and ideals and outcomes implicit therein, e.g. integrated, inclusive, reducing the incidence of challenging behaviour, minimising the adverse effects of health problems to improve the quality of life and making the range of service provision available to all users. Quality will also be defined from the individual professional perspective of workers contributing to a multi-disciplinary assessment each of whom must be given due weight and whose partial view must be brought together in a holistic assessment which sees the person as greater than the sum of these parts. From the government's perspective quality services are seen broadly as those which: seek to maximise independence and community involvement; respect and seek to meet the needs of user and carers on an individualised needs-led basis; and those which reduce stress upon carers. While we have been busy developing quality services for students with less significant and profound disabilities I feel we are much less confident, and to some extent guilty about what constitutes quality services and how to develop such services for those students who have much higher dependency needs and more significant and complex health care needs.

In principle the way forward is easy, if we start from Harry Stack Sullivan's premise "we are all more or less simply human". The range of service provision for those users, often described as having profound and multiple disabilities, should be the same as for other students with special needs. What is needed is the commitment to make things happen and challenge assumptions about users, the phrase 'champions of change' comes to mind and the fact that the TSG has representatives from providers across the borough encourages people to seek solutions creatively rather than simply say "It can't be done". there is a good deal of peer group pressure within the TSG to drive things forward. In addition, the fact that the school responsible for young people with more profound disabilities is forging closer and much earlier links with the special needs staff at the local FE college is more likely to create some radical outcomes for their students. The staff in the supported employment service are looking to place young people with profound and complex learning difficulties in real work situations. Clearly this is not employment as we normally perceive it, but to be in a real living sensory environment for part of the week must be better than an artificially created experience in a segregated environment, and with the potential but very real added bonus that other members of the work force have an opportunity to meet and make a relationship with the young person. This work is in its infancy, it may not work but we are very optimistic about making itsome of the initiatives taking place within my own local authority which we hope will help to improve the quality of life and help to reduce the trauma of transitions for users and carers alike.

The TSG has proved a most influential forum for debate and the generation of ideas to maintain the momentum of development. However, despite the work that has been done I am acutely aware that much remains to be done before we can be confident each user and carer is well served by the process.

Ken Stapleton  
Team Manager  
Care Management and Social Work  
Oldham Learning Disability Service  
Broadway House  
Broadway  
Chadderton  
Oldham

Tel: 0161 911 3868

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*After School - What Next? Developing multi-agency transition policy and Practice* by M. Routledge. NWTDT 1998



	<ul style="list-style-type: none"> <li>i. Review Statement and current progress</li> <li>ii. Explanation to Student and Carer re. purpose of the "14+ Review".</li> <li>iii. Begin the process of identifying aspirations and future need of student and Carer or assisting with developing aspirations.</li> <li>iv. Identifying tasks / needs to work on to assist Student with transition to adult life.</li>   <li>v. Role and commitment of other Agencies, e.g. Health, Careers, LEA, Voluntary organisation.</li> <li>vi. Produce written Transition Plan for Student and Carer.</li> <li>vii. Arrangements for Review and co-ordination of Transition Plan.</li> <li>viii. Request from LEA to SSD re. status of Student as a "disabled person".</li> <li>ix. Flagging up potential future involvement of Adult Services (SSD / Health).</li> <li>x. Copy of Minutes of Review, including TRANSITION PLAN, to STUDENT, CARER and relevant stake holders within 3 weeks.</li> <li>xi. Date set for next review of Statement, Transition Plan and Action Plans (YEAR II).</li> </ul>	<p>Head / Senior Teacher</p> <p>LEA requests of SSD.</p> <p>Head / Senior Teacher</p> <p>Head / Senior Teacher</p>	<p>Curriculum issues within extended education. Discussion of needs of Student if planning to leave School at 16 years - if so taster sessions will need to be incorporated specifically in Transition Plan.</p> <p>Consideration if FEFC application may be relevant at some stage.</p> <p>Student and Carer must be central and be seen to be central, to the whole process. How do we ensure this happens at each Review?</p> <p>1986 Disabled Persons Act.</p> <p>"relevant stakeholders" would include Advice Givers, Statutory Assessment Officer, any worker named on the Action Plan.</p>
<p><b>YEAR 11</b></p> <p><b>Autumn - Spring Term</b></p>	<p>1. Review of Statement and Transition Plan.</p> <p>Review Action Plan for Year 10. Identification of any gaps. Identification of plans for Year 11/12. Curriculum issues is extended education linked directly to Transitions Process (Learning for Life).</p> <div style="border: 1px solid black; padding: 5px; width: fit-content; margin: 10px auto;"> <p>Advice and information re. Welfare Benefits.</p> </div> <p>2. <b>EARLY REFERRAL PROTOCOL</b>  For Students with complex / future accommodation needs Children's Team to refer to Team Leader (Adult Services LDS or Physical / Sensory Handicap or Mental Health) OR Nurse Manager Adult LDS under the <b>EARLY REFERRAL PROTOCOL</b> for Care Management Assessment which will be undertaken in partnership with Student's key worker within Children's Services.</p> <p>Initial transfer of information from Children's to Adult Services in order to make appropriate and accurate assessment of needs.</p> <p>Care Manager allocated</p> <p>Nursing Staff allocated where necessary (eg. health care needs, challenging behaviour etc.)</p>	<p>LEA / School Head / Senior teacher to chair STUDENT &amp; CARER Key Teacher Careers SSD / Health other relevant Advice Givers</p> <p>SSD / Trust - keyworker from Children's Service.</p> <p>LEA: Statutory Assessment Officer for Students in out of borough placements.</p> <p>Student &amp; Carer Keyworker Staff in School</p> <p>Health workers: GP, Consultant, Community Physician, Community Nurse, Physio., Speech Therapist, OT.</p> <p>Team Manager (Adult Services)</p> <p>Head of Nursing (LDS)</p>	<p>Preferable to attend in person. Written information if unable.</p> <p>Issues of confidentiality will need to be addressed with Student &amp; Carers.</p> <p>May be issues of Risk to assess.</p>

## The Successes and Challenges of Transition

My research has been concerned with transition from schools for children with moderate learning difficulties. I have been following all school leavers from three special schools in two authorities for the 6 months before they leave school to the first year to 18 months after they left. My findings are a mixture of positive and not so positive issues which I think might be relevant to all learning disabled school leavers.

### Positive Aspects

*Teachers and College Staff* - A positive aspect of transition highlights the importance of relationships within the schools and colleges. The optimistic attitude of the teachers, and their involvement in the lives of the school leavers took their role as a teacher/college tutor beyond their 'duty'. This was apparent both through observations, through listening to staff recall stories, and also through the interviews with the young people, who often spoke favourably about their teachers. Many teachers fulfilled a pastoral role which they felt to be an aspect of their job. Although not necessarily part of their job description, it was necessary to satisfy the needs of the young people who came to rely on them.

An example of this was shown by a part time member of staff at one of the colleges who was also a local employer. When he needed staff, he encouraged students who were on college links from one school, to apply for his vacant positions. The interesting part of this was that the college tutor explained that he specifically wanted to employ one of the school leavers because he was "a bit of a wayward lad" - normally the reason not to employ someone. It would be expected that teachers at schools for pupils with severe, profound and multiple learning difficulties might perform this pastoral role to an even greater extent and therefore create an even stronger link with the young people.

*Work Experience* - The majority of the school leavers were involved in one or more work experience placements. Work experience was mentioned by a lot of school staff, parents, and the young people as a positive aspect of transition. It was thought to be working well and the schools had concentrated on developing good links with local industries. This development of school-employer relations has meant that some employers have taken pupils for a number of years, and in some cases this has led to employment.

*College Links* - Possibly most striking of the positive aspects of the system, is that of the success of the links between the school and the colleges. The importance of this link cannot be stressed enough as the majority of the school leavers said they wanted to go to college, and then went on to college after leaving school. Indeed, few adolescents make the transition to adulthood directly from school anymore.

### Challenges

On a less positive note, there also seems to be a number of factors that people in various positions all feel could be improved.

*Social Integration* - Through completion of a quality of life questionnaire, it became apparent that the school leavers had relatively empty social lives, and that this did not improve after they had left school. One of the questions asked about the number of school clubs they participated in, and 88% of the young people answered 'none' to this question. Such a high percentage of pupils who are not involved in any school clubs is a concern, especially as other studies have found that social participation for youth with moderate, severe and profound and multiple learning difficulties is less than that of non disabled youth. A worry for the future is that there has been research that shows that even thirty years after leaving school social participation was still considerably less than average (Atkinson, 1984).

*Housing* - Housing was mentioned as a problem that was not being addressed, and certainly from observations made in the schools, there was not any information regarding housing at the schools. At the colleges, housing was a subject area that was covered in the supported courses. However, despite this, it was an issue that was raised by parents and professionals, so it is possible that by the colleges addressing the issue rather than the schools, it was felt to be leaving it too late. Some of the participants in this study did face housing difficulties, and moved out of their parental homes during the course of the research. Even where the issue of housing was being addressed within

the colleges, it was done in a theoretical context such as how to look for housing in a local paper. It did not appear that the schools or the colleges had any links with housing associations, or with council housing departments.

*Parental Involvement* - Parental involvement is an area where several issues have been raised. Attempts were made to involve parents in the research by sending letters home from school. Out of a possible 90, there were only three responses. Lack of parental involvement in the transition process was seen as a problem by the teachers from all schools. The head teachers, class teachers and careers teachers had all tried to encourage parents to become more involved in the schools but they generally felt that they had had little positive response.

*The Future* - Despite school leavers being able to state a desired post school destination, and the majority of them having enjoyed school and feeling that it had helped them, many of the people I spoke to did not seem positive about the future. They spoke about leaving school being difficult because they anticipated not being able to get employment, and ending up at home being bored. The negativity about the future was not just confined to the school leavers. In some instances past experiences seem to have had a negative effect on some of the school and college teachers. One college tutor spoke about past groups leave college and get a job or go on a training scheme but end up back on benefits within a year.

*Disappearing from the System* - The final and possibly most significant challenge, is that of the relatively large number of young people who 'disappeared' and were unable to be traced, not only by me for the purpose of this research, but also by the schools, the careers office, and other service providers. It is worrying how early and quickly young people disappear from the system. On initial visits to the schools, it appeared from lists of students enrolled in the schools, that the total number of participants would be 90. When the interviewing started only 60 students participated. In a small number of cases, this was due to longterm sickness or some other unusual circumstance. However for the rest of the non participating enrolled students, the reason for their non participation was either that they had been excluded from school, or that their sporadic attendance happened not to coincide with my visits to the schools. Attempts were made to contact non-attenders, but this was largely unsuccessful. When I tried to contact the people I had spoken to a year later, I was only able to trace 26% of them.

This phenomenon is not an isolated case. As Coles (1995) points out, past researchers that have traced special school leavers have had similar experiences. Coles refers to a number of researchers (e.g. Clarke & Hirst, 1989) who found that young people with special needs simply disappeared and were untraceable. Researchers were typically unable to trace the status of more than one in five of their sample. Of course it is possible that all of these young people have gone on to fulfilling lives, however, it is difficult to see how appropriate services can be provided if people cannot be traced.

Despite numerous challenges to the system, the positive aspects to the system were weighted more heavily in the overall success of school leavers. There are a great deal of positive things going on in the schools and there also seems to be a genuine wish from everybody involved in the transition process to try to improve things further. The real test will be what happens to the school leavers over the next few years.

### **Sue Caton**

33 Acton Avenue  
Appleton  
Warrington  
Cheshire WA4 5PS  
Tel: 01925 860 372  
email: SUECATON@aol.com

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# ***The Circles Network CREDO Project***

The Circles Network CREDO Project is a 2-year national project funded by the National Lottery Charities Board and is designed to support young people between the ages of 13 and 19 who are perceived as having profound and complex impairments. There are currently 2 projects - one in England and the other in Northern Ireland, both projects focus particularly on the move from childhood to adulthood.

CREDO stands for Creating Real and Equal Development Opportunities and focuses on responding to the wishes of each young person, with the aim of making a positive contribution to society.

Support is achieved through developing a circle of support. A circle of support is a group of individuals who meet together with the sole intention of supporting a person (the focus person) who is isolated from community or, who is in danger of becoming isolated. This group is made up of those people who know the focus person best and who are prepared to listen deeply to them, assisting with the realization of dreams and ambitions. Parents, brothers and sisters, friends and committed support workers all work together to draw out the information that will give the person a 'voice' and will represent their contribution towards the planning of their life.

With regard to the CREDO Project, this planning takes the form of looking at what the young person wants after they leave school and how their needs can best be met. As is commonly known, this time in a young person's life is often called 'transition' and for many young people is a time of uncertainty, risk taking, experimentation and making choices. It is also the time when the majority of us plan and look forward - with some excitement - to our adult lives. It is a time of opening our minds and dreaming, of connecting with others and finding out who we are. For those young people who are perceived as having complex needs, the situation is commonly very different.

For the young person and often their family, the 'transition years' are commonly dominated by feelings of worry, uncertainty, fear, guilt and apprehension. Statutory services are often not well co-ordinated and information regarding services that are on offer and decisions that need to be made are left far too late. In addition there are commonly limited services available, resulting in a lack of choice and creativity and a creation of dependence on systems and families. There is much information that tells us that this is often a time that families find themselves pressurized often against their wishes, into using residential services - due mainly to a lack of adequate available resources available to the family as a whole.

Person Centred Planning is a process of planning for individuals, that is alive and active and enables the person to be central and to take control. With the CREDO Project, it is the young person with complex needs that owns and controls the process with the assistance of those people in their life who know them best i.e. their circle of support.

So often in more traditional styles of assessment, the comments and views of a young disabled person and their family come after all other professionals involved, and feature less in regards to content and more importantly, value. By using person centred planning techniques, the young person and their family are empowered to dream and to make life choices with the support of those who love and care for them.

The CREDO Project does involve other professionals, from education, social services departments, health and voluntary agencies; however it is the young person and their circle of support that the project is in direct collaboration with rather than with other organisations. The ideal situation is then to work 'alongside' agencies and providers - with the young person remaining in complete control of the planning process.

Through the process of person centred planning, the young person is encouraged to dream and to look widely at what they want from life and how they want to spend their time. As this is a way of viewing things that does not only consider existing service provision, the situation may be that the young person - with support from their circle, will push the boundaries of what services are currently available for young people with profound and complex impairments. This process is creative and focuses on areas that are often not emphasised enough in more traditional style assessments such as; the young person's dreams, goals, gifts and their individual life story. The plan then guides the young person towards their future with the aim that they are a contributing citizen participating in community life. With a little careful thought, commitment and redirection of resources, it is possible to design and create a responsive support system that ensures that the young person can move towards a positive future.

As all of the young people currently involved in the CREDO Project have their own unique method of communicating, it is essential that it is those people who have spent time with them and who listen deeply and value each way of communicating who assist in knowing and at times 'best guessing' what the dreams of the young person are and how they would most like to live their life. This understanding allows for a 'tuning in' to each young person and will guide us to what brings them joy, excitement and engagement in life and away from experiences that cause pain, sadness, boredom and frustration.

For some young people who are either coming to the end of their school education or are now using adult services, it has been necessary for their circle of support and the CREDO lead facilitator to take a more active role in ensuring that the young person is being listened to and that they are receiving the support that they need to live their lives as they wish. This has taken the form of the project assisting with the recruitment of personal assistants, attending service reviews and supporting the young person and their family at various meetings.

*Kerry is involved in a supported living scheme and her circle is assisting her to build up a picture of her ideal home and the support that she will require to live her life as she wants. Kerry's Social Services department have asked her circle for this information as Kerry's circle is made up of the most important people in her life, who truly know her unique methods of communicating and how she indicates her preferences and her dislikes. Kerry's Mother - Jeanette, feels that everyone is now focussing on Kerry's needs, rather than Kerry 'fitting in' somewhere that may not be appropriate for her. Jeanette says that "we can now start with a clean sheet and with the support of Circles Network and everyone else who cares about Kerry, can 'map out' just what Kerry's ideal home would be".*

For other young people, planning has begun at a time when serious thoughts are just being made towards the future.

*James is 17 years old and his long-term carers are very pleased to have found out about the CREDO Project because of the anxieties that times of transition can bring. James's circle meetings are proving to be of focus to those people who are involved in James's life and who individually would find it hard to know how to continue from now. Although the planning process is in its early stages, James is already inviting his peers to his circle meetings and working on how to be more independent and having more life choices. James's school have been enthusiastic in their approach to the project and will welcome James's contribution i.e. his Person Centred Plan, to his next review as a valid and extremely important document.*

It is through developing circles of support that we build more inclusive societies and individuals strengthen their natural networks and friendships with others - with the ultimate aim of interdependence. This is particularly important for young people with profound and complex impairments as so often, the majority of others in their life are paid to provide support to them. People who commit to a young person who has profound and complex impairments, are concerned about that person's future, they stand with them during difficult times, they help problem solve, they work to identify and create opportunities for them and they join in celebrating successes. They want to continually grow in knowledge of the person, especially of the person's gifts and capacities and to actively assist the young person to expand relationships with others who may come to care about them also.

The CREDO Project will share examples of success and challenge, highlighting good areas of practice. This will be achieved through arranging a series of regional awareness events over the life of the project, producing a video (late 2000/early 2001) and hosting a national conference (planned for Spring 2001).

If you know of a young disabled person who may be interested in becoming involved in the CREDO Project or if you would like further information on the project or on Circles Network providing training and consultancy then please contact:

**Nadine Jay**  
CREDO Project, England  
8 St Johns Road  
Fletton  
Peterborough  
PE2 8BN  
Tel: 01733 551253  
Email:nadine@circles.free-online.co.uk  
Email:wendy@circlesnetwork.fsnet.co.uk

**Wendy Buchanan**  
CREDO Project, Northern Ireland  
The Manor House  
51 Mallusk Road  
Newtonabbey  
BT36 4RU  
Tel: 02890 833430

Or visit our website: <http://www.circlesnetwork.org.uk>

# EXPLORING CHOICE

The Foundation for People with Learning Disabilities is now disseminating the findings of the **Choice Initiative**, a programme of five innovative projects (1997-2000). These explored how people with learning disabilities and high support needs could express their wishes and bring changes to their lives.

## The 5 projects

*Choices* at the Markfield Project, London about choice in the community

*Friendship Train* at People to People, London about choice in friendship

*Futures Project* at Choice Support, London about choices on leaving school

*Pathways to Citizen Advocacy* at the British Institute of Learning Disabilities, Kidderminster,  
a training resource for advocacy groups

*Step Out* at L'Arche Liverpool about choice in work

The Foundation has produced *Choice Discovered*, a training resource comprising a video and written materials. It is aimed at anyone working to support people with learning disabilities who have little or no verbal communication. An introduction to the key principles of communication and ways of discovering choices, it can be used by anyone who has the confidence to run training courses. The video shows some participants, supported by staff making choices on three of the projects. It is used as a discussion point in the training.

It will be launched at a day conference, *Choice Discovered* on November 9th 2000 to be held at the Foundation. John O'Brien will be a keynote speaker. It will be of particular interest to managers and frontline staff.

The report, *Everyday Lives Everyday Choices*, explores themes relevant to choice for people with high support needs such as communication, risk, advocacy, staff issues, work and community activities. Each chapter is introduced by a researcher or professional with expertise in that area and then the findings from the projects are discussed.

Here we give you a flavour of the report by reproducing the concluding reflections. The Choice initiative was set up in the belief that people with learning disabilities and high support needs have the right to play their part as full citizens. For this to happen

*they.... need people attuned to listening to what they are saying without words and a huge amount of support alongside a wide range of opportunities. (MHF 1996:103)*

During the past two and a half years, we have developed our vision of a future where people with high support needs are able to take more control over their lives and decide on what they would like to do and how they would wish to live. We have been encouraged by the imagination, resourcefulness and determination of all those who have participated. We believe that continuing progress depends on entitlement to support and services that promote choice and social inclusion.

**For everyday lives, everyday choices, each person with learning disabilities and high support needs should have the right to:**

- communicate in a way that is appropriate to them;
- be presented with a range of choices that are appropriate for them;
- make choices about how they spend their days;
- make choices about where they live and with whom;
- have the opportunity to make friendships and relationships;
- have their friendships and relationships respected;
- be involved in risk assessment procedures that address both empowerment and protection;
- have an advocacy partner if they so wish;
- have sufficient staff to lead a full life in the community;
- choose staff who value and respect their autonomy;
- have access to transport to enable them to participate in the community;
- have sufficient financial resources, including the opportunity to have Direct Payments if they so wish;
- have their cultural, religious and ethnic backgrounds respected.

### **The impact of choice**

The work in the projects has demonstrated that people can make choices in areas such as how they spend their time and how they live.

*Clients have shown greater happiness in their lives, just through this one day support. It's meant so much to people and changed different things in their lives and changed how they see themselves within the community.*

As John O' Brien has said in the introduction, "these projects demonstrate that many people with substantial disabilities respond to project workers' interest in knowing them, accepting direction from them, and working with them to open new possibilities."

### **The importance of communication partnerships**

The key to the Choice Initiative has been the relationships that have been established over time between the participants and the project staff. Communication, if it is to be positive and meaningful, has to be based on trust. To have the appropriate tools is only part of the story. In some cases, gestures and facial expression alone have been the only clues to participants' wishes. Often others close to the person have also offered insights. There has been soul searching about the reality of people's choices and the most appropriate ways to enable each individual to make meaningful decisions.

*It really is getting to know the person, getting to know their carers and their families... and then just trying to build up a picture of what they enjoy and trying to extend what they are already doing handing choice over gradually and finding people's levels.*

*It's a fine line to make sure that the support workers are not influencing choice too much.*

Support workers also have needed to assist participants to transform their wishes into reality, so that they would be motivated to communicate as they saw results.

Project workers have found real satisfaction in seeing the way participants' lives have been enriched.

*If you want this, if this is really what you want, then you can and I would like to be there to help you.*

*We 've wanted to open doors for people.*

### **Support for staff**

In trying to help others to capture their dreams, project workers have also needed support, through appropriate training, often based on experiential learning and exploring values.

*It's been really good to talk about our experiences.... we've all shared the same things really.*

They have valued sympathetic line managers who have been prepared to work alongside them, as well as helping them to explore the issues the work in the projects has raised.

### **Risk**

In particular, it has been necessary to be sensitive to the risks involved in promoting choice and awareness of the duty of care. The Choice Initiative has shown that there are emotional as well as physical risks. One or two people have turned their back on choices they have made. This is a not unusual experience, but it does also serve as a reminder that some choices may need to be introduced after great thought and preparation and that they may not always turn out as expected. The risks associated with choice need to be fully understood and accepted. Citizen advocates can play a key role in supporting their partners to make appropriate changes they would wish to bring to their lives.

### **Friendships**

Choices do not always need to involve intense activity:

*She enjoys being round people, having a cup of tea; spending a long time sitting... and watching people.*

Interwoven in the life of the Choice projects was the importance of friendships. The Choice Initiative has shown that

there needs to be the wider acknowledgment of, and respect for, the importance of supporting people with high support needs to make and sustain ordinary friendships.

### **Obstacles to choice**

Support staff have also experienced sadness and frustration at the restrictions many people with high support needs experience, for example, because of, poverty, lack of transport, insufficient staffing, unsympathetic employers and inadequate support to family carers.

*We've lost clients who were initially involved in the project through lack of resources, through changes in staff...*

*I think the main obstacle is a general attitude of society... Giving people access to mainstream facilities including people in all society's activities is not a general attitude.*

### **Future challenges**

There are real challenges if choice is to become the reality in the lives of people with learning disabilities and high support needs. Some practices will need to change, but above all there needs to be acknowledgment people's wishes should be sought and respected. For all who seek to find ways to empower people with high support needs, intuition and empathy are important alongside analytical skills. Roger Deacon, Head of Adult Services, Surrey has written in an unpublished document:

*(There is) the need for us all (i.e. all stakeholders) to expand our imagination. Imagination is the key to creating opportunities, achievement and realisation. Often it is our lack of imagination that restricts our/people's belief in what people with learning disabilities and high support needs are capable of communicating and achieving.*

To order publications ring 020 7535 7441

*Everyday lives, everyday choices* for people with high support needs £22.50 plus 10% for package and postage

*Choice discovered* £80 plus 10% for package and postage

### **Hazel Morgan**

Programmes Manager

The Foundation for People with Learning Disabilities

20/21 Cornwall Terrace

London NW1 4QL

Tel: 0207 535 7400

e-mail: mhf@mentalhealth.or.uk

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## ***request for help from Abbey Court School***

*We are an SLD school and have recently moved into a new (adapted) accommodation in Kent. We need to convert 2 external courtyard areas into multi-sensory environments for our pupils. We are struggling to find companies who can create appropriate environments for us. We have a relatively healthy budget for the project. Can you help us find some contracts or offer any advice?*

*Many thanks*

***Karen Joy - Headteacher***

***e-mail: CourtAbbey@aol.com***

***Abbey Court School, Rede Court Road, Strood, Rochester, Kent ME2 3SP***

***Tel: 01634 718153***

# SENSORY ENVIRONMENTS FOR PUPILS WITH PROFOUND AND MULTIPLE LEARNING DIFFICULTIES: AN UPDATE

## Introduction

This paper details the discussions of the Cambridge University working party at their meeting in March 2000. The first meeting of this group of multisensory room (MSR) practitioners was in October 1998, as reported by Richard Byers in PMLD-Link. The group has met regularly since then.

The purpose of the meeting was to discuss:

- Staff training
- Policy, planning, assessment, recording and reporting
- Good practice in the MSR: a sharing of ideas
- Health and safety issues

## Staff Training

Staff training is essential to the appropriate use of the MSR. Technophobia and lack of purpose in the MSR promotes only poor practice and apathy. Staff must learn to facilitate pupils' progress in the MSR and acknowledge themselves as the most valuable 'resource' in the room.

Appropriate and comprehensive staff training would enable:

- The use of the MSR as an educationally viable tool: enabling access to the curriculum
- Development and consolidation of skills learnt in the MSR to the wider curriculum
- Reduction of over dependence on visual stimulation effects
- Consistent, effective and appropriate use of the MSR by all school staff involved with each individual child
- Reduction in the incidence of sensory 'bombardment'
- Recognition and utilization of the learning potential of the MSR
- Good knowledge of the equipment in the MSR
- A sensory skills baseline assessment to be carried out, providing the starting point for an individual programme to be written
- Staff to focus on the child and not the equipment
- Accommodation of pupils' different learning styles
- Staff recognition that their 'experimentation' time is valid and essential but not during the pupils' time
- Ability to extend the work inside the MSR outside to the wider environment, using portable equipment and providing advice and support to other teachers.

## Individual Programmes

The group also discussed the role of a 'MSR co-ordinator'. As Porter and Miller (1999-2000) found out 'Responsibility for the MSE has varied across settings'. Technology teachers, LSAs and many other professionals within the school may be given the job of keeping the room in good working order and ensuring good practice.

The division of this role was discussed:

1. Maintenance/detailed equipment knowledge/provision of support documentation and instructions.
2. Policy development and professional development of staff.

Should this be a dedicated full-time role? Is splitting this role as suggested a more effective solution? Does having a MSR co-ordinator mean that other staff don't take responsibility for the MSR? Further discussion is ongoing!

## Not just light!

The overdependence on visual stimulation techniques within the MSR was discussed. Even the name of the 'area' could indicate the philosophy behind it i.e. 'light room', 'dark room', 'studio' etc. As communication occurs in a 'multi modal' manner so should good practice within the MSR. The group noted with relief the development of the use of music in the MSR from the 'pan pipes' era to the use of anything that 'goes' - from the Spice Girls to Land of Hope and Glory! Vibration was felt to be equally important as light to visually impaired pupils, and it was noted that little research on vibration and visual impairment was available. The interlinks between light, sound and vibration were discussed.

## Good practice in the MSR: a sharing of ideas

Various ways of working in the MSR were shared. These are summarised as follows:

- Capitalizing on other skills developed incidentally alongside the aim of the session and then generalizing these to outside the MSR.
- Use of vibration by placing stereo speakers up against sofas and inflatable chairs, making it more accessible.
- Developing exploring skills through offering different textures of 'rubbish'

- Arranging group work around a theme, story or a creative writing activity
- Using the Solar 250 with digital photos of pupils for 'hello' session (three copies of acetate give a better colour density)
- Importance of back projection to make the image more accessible to the pupils
- Using food to develop use of senses through taste, touch and smell, with use of switching systems in food technology session.

### Health and Safety Issues

The group discussed the importance of health and safety issues. The British Standard is a lengthy and expensive process to achieve, which many companies are unwilling to pursue. It was felt that the MSR market is commercially driven rather than professionally driven, which complicates the issue. The readiness of purchasers to go for the cheapest rather than the safest option was acknowledged. However, it is up to the manufacturers themselves to be responsible for the safety of their products, not the consumer. It was felt appropriate for a consumer association to be approached for advice in this matter. A working group has been established to offer further research on this subject.

### Closing Comments

As Richard Byers said in his last article, the group will be meeting again in the Autumn term. Participants would be very pleased to hear from other practitioners who may wish to make contact with the group in order to

- Make comments on any points made in this article
- Report on initiatives in other parts of the country, or raise further issues for discussion.

If you are interested please contact

**Richard Hirstwood**  
395  
7 Ellesmere Road  
Morecambe LA4 4LF

Tel: 01524 426

Fax: 01524 417829

e-mail: richard@hirstwood.edi.co.uk

## SHARE AND SHARE ALIKE

The more 'individual' the needs of any learner, the harder it is to find resources to meet them. Although this will always be the case, help is now at hand in the form of a new DfEE-funded Web site called *Inclusion*.

Part of the Government's initiative to fight social and educational exclusion, this site is designed to help teachers, learning assistants and parents find resources to meet learners' needs, however obscure. Essentially an on-line catalogue, *Inclusion* already has links to more than 400 resources featuring a wide range of special educational needs. Users are presented with a series of inter-related questions, and they select from a menu of answers all the features they are looking for. This enables the search engine to find resources which match these criteria - and can result in a list of publications, information sheets, ICT resources, physical aids and links to other organisations.

On-line catalogues are nothing new, of course, but *Inclusion* aims to be different by inviting a wide range of people to contribute to its content. It's not only agencies, organisations, LEAs, software developers and publishers who are being asked to put their resources on-line, it is classroom teachers in special and mainstream schools too. This acknowledges the fact that amongst the whole community of people working with special needs there is a wealth of experience and expertise which needs to be shared with a wider audience.

Anyone using the site is able to recommend further resources for listing, provided that they are accessible via the Web. Catalogue entries are then scrutinised by a team of moderators to make sure that they are accurate and reliable, so users can be assured that resources really do what is claimed. The more resources listed on the site, the more helpful it will be - and the more it will be genuinely inclusive. Currently targeted on special educational needs, the focus is about to move towards gifted and talented learners and the achievement of ethnic minorities. In time, lifelong learning will also be addressed, so the needs of adult learners and continuing education will be included.

### **Meeting personal needs**

The site also aims to be personal: by keying in their particular interests, users can ask to be informed by e-mail of any future resources which match their criteria. This will be particularly helpful to busy teachers who don't have the time to check out Web sites as often as they'd like. Another useful feature is the facility to refer queries to an expert panel: if a search of the Web site fails to deliver what a user is looking for, they can post their query and expect a reply within days.

Also on the site are key documents from the DfEE and other agencies, to help teachers keep up to date with curriculum requirements, the Code of Conduct and public consultation. There's also a News area so that items of interest to the world of special needs can be highlighted.

### **National Grid for Learning**

The Inclusion site is part of the National Grid for Learning (NGfL) and managed by Becta. Special needs has long been an important part of Becta's work, as many practitioners know. Already on the NGfL is a contributory database to allow teachers to share resources and teaching approaches and there is a growing number of discussion forums for SEN co-ordinators and others. The SLD-forum is a good place to start if your concerns are with profound and multiple learning difficulties, but there are others too, including one forum for teachers of the deaf and another for those supporting learners with physical disabilities.

Joining a forum (or just observing what others are discussing) is easy: visit the NGfL at <http://ngfl.gov.uk> and follow on-screen instructions.

### **Networks of expertise**

As the Web becomes embedded as a means of communication, more and more organisations are using it to advertise their services. This embraces not just commercial providers but voluntary organisations, community grids for learning - and even individuals who realise that they have specialised knowledge. If you or your colleagues have created information sheets, case studies of good practice or guidance on teaching strategies, why not share them with a wider audience? All you need is a Web site, so that users can link to your pages and download information.

This is a major opportunity to make inclusion a reality and to end the isolation and lack of support that teachers can feel - particularly those in mainstream education who are desperately in need of specialised information. As with any other database, Indusion can only be as good as its content, and the more resources that are added, the more likely it will be able to match users' requirements.

You can find the Inclusion site at <http://inclusion.ngfl.gov.uk>. Visit it and see how it can help you to support your pupils and, if you have resources which you'd like to share, add them to the site.

**Terry Waller**  
Education Officer, Special Needs and Inclusion  
Becta  
Milburn Hill Road  
Science Park  
Coventry CV4 7JJ

Tel: 01203 416994  
e-mail: [Becta@becta.org.uk](mailto:Becta@becta.org.uk)



# JUAN

Nine years ago we had our third son, Juan. After some vicissitudes, it became clear that he had severe brain damage and would develop severe disabilities.

Although we could always choose good therapists (physical, occupational and speech therapists), we felt that there was a mismatch between what he received at the therapies, and what we felt he should receive. They proposed some activity to him, expected him to do something, he did not do anything, and they said: "he cannot". At home he shared all our activities, including our social life, and he never disappointed us. He always seemed to understand well enough what was going on. I must point out that he always had very good medical care.

He went to the University Nursery until he was three years old (I am a University employee). He then entered a special school for children with physical disabilities. We were not satisfied with the pedagogical and therapeutical approaches. We almost suspected they had no approach at all. Besides, there were no hints of a decision to attempt integration with conventional environments, not even with children with milder disabilities at the same school.

At the same time we started to notice that many school aged children were excluded from special schools, because teachers said they could not learn any more. There were even children that were not accepted in school after assessment.

I got in touch with the Argentine National Federation for Mentally Disabled People (FENDIM) and started to read about disability, but the articles I read did not talk about Juan. When I discovered the term PMLD through MENCAP's leaflets, I thought this is a way of labelling people, I could search in this direction (books, articles and Internet) and started reading and learning things that changed our life completely.

I believe that Juan needs at least the following

- That his right to education be fulfilled
- To be included in common social and educational environments
- To follow a curriculum
- To be assessed for goal planning and not for labelling and exclusion
- To have an adequate form of measuring achievement
- To have access to a form of alternative communication that will allow him to express himself with freedom and with different people, and not just to answer simple questions to well known carers.

But I know that not until every child's rights are fulfilled and equality of opportunities are real, will each individual child and adult be safe.

About the first issue, a group of committed specialists studied the rules of the Department of Special Education of the Government of the Province of Buenos Aires, National and Provincial Laws and International Documents, and we are now presenting our demand before the authorities.

For the rest we started individual action, because we do not have the right to let Juan's time go away uselessly.

During 1998 and 1999, he attended a normal kindergarten, not incorporated into the Ministry of Education (as he was not being referred from a special school, because they considered him not suitable for integration). He had a support teacher, and at the same time he continued to get his normal private therapies.

This teacher was to provide support for Juan inside the kindergarten, ensuring that he could take part in all the activities proposed by the kindergarten's group teacher. They were also to have a working time of their own, apart from the group's activities. She used Flo Loghorn's Programme of sensory stimulation. She wrote a daily record of his activities and emotions, and we did the same at home, so that a channel of communication was open about his life in both places.

By the end of 1998 we started to use pictures and photographs to refer to daily events and known objects. We started to give him the opportunity to choose his clothes, or what activity he wanted to do. He told us what he had done at school or at home with these images. As he likes letters and words, we offered them to him since he was five. He can recognise some words and he is permanently exposed to written language.

Through bibliography we learnt about information technology, and after a visit to Great Britain he got his first switch and programmes for the PC. Now he has access to toys, radio and tape recorders through a switch and an interface. He has a simple one message communicator. He uses Mayer Johnson cards on a board to express choices, emotions or to tell others about events.

After a year of developing these activities, Juan could be assessed at the only IT Centre for Alternative Communication that works with children with very complex needs in Argentina. They made a programme for Juan and we hold periodic meetings for new assessments and goal planning. This year he has just started going to an Institute for visually impaired children that is willing to work in this direction, and will foster his integration to a mainstream school.

This is the first time that Juan's educational programme is not entirely in his parents' hands. But we have to face a struggle against Educational and Social Security authorities:

- Until now we have supported almost all of Juan's activities and therapies with private funds.
- During 1999 he was assessed at the only state-owned special school that could accept him, after Government regulations. The interdisciplinary team considered that "his motivation was absent", that he was "a multiple disabled child with 7 months of intellectual development " and that there was "no pedagogy for multiple disabled children". They proposed to have him at school for an hour and a half twice a week to see what "he showed to be capable of". We considered that this assessment was an autoprophyesy that told more about a working style than about Juan, and decided not to accept it.

When I was sure that Juan was improving his skills for communication as well as his behaviour, his abilities to show cognitive progress and his social skills, I started to share what we had learnt with other parents during informal meetings, through collaboration with the only non profit association for children with very complex needs in La Plata. I am working as a volunteer at their Day Center for children excluded from special school. We are taking the first steps towards sensory stimulation, communication, and incorporating IT for these purposes.

We are working on the idea of assessment and goal planning, development of a curriculum, the importance of planning and keeping adequate records. But above all we are establishing the certainty that every child is educable and that apparent failures are challenges to the teacher's creativity and imagination to make tasks more appealing or to divide them into more simple steps.

What I have said about the difficulties and obstacles that Juan faces is just the case of hundreds of children in our Province, and probably in our country. I have realised that not only the attitudes towards PMLD children are unfair: in fact, there seems to be no knowledge about these people. I have found that teachers, therapists and policy makers do not know about bibliography, academic and applied advances, or legal issues and rights concerning people with severe, profound and multiple disabilities. There are no qualified people to work with them and the result is that they are forgotten in all planning, and continue to be absent when they become young adults. Therefore they are unknown to the local communities. They and their families never receive the support they need, and these events as a whole add an amount of additional disability to each one's basic situation.

The qualification of at least a small group of interested people is the only way of changing the attitude of specialists and community in general. This, in time will help people to recognise violations of rights, and fight against them.

Elena dal Bo  
Calle 16 no. 37  
1900 La Plata  
Argentina

## All Children Belong Together

Transition from childhood to adult life for many people with physical, intellectual or emotional difficulties is a journey often fraught with anxiety, frustration, disappointment; leaving individuals themselves, their parents and other family members fearful and uncertain of what lies ahead. The journey is made easier only when communities embrace fully the core values of inclusion and respond with love, concern and support for those previously shunned, feared or blamed for being different.

Historically, in-built perceptions of society have led many to view people who are different with fear, suspicion and prejudice. In today's world disabled people are still viewed as sick or pathological, wholly innocent or as eternal children in need of fixing, improvement, protecting or charity. As a result many are left trapped in a parallel world where opportunities to play a full part in the life of the community are severely limited.

How can we as a society take the first steps on a road that will bring a more tolerant society? Negative perception fear and prejudices can all be altered through education. In Ontario, Canada the phrase 'inclusive education' was used to describe an educational system where money and resources, previously pumped into maintaining a separate two tiered system, were now being re-channelled into a revolutionary new system; one where all children were educated together in the same mainstream classroom. In Canada this system has operated successfully for a number of years.

In Scotland, many problems remain unresolved. Provision across the country for children with special needs is diverse with many local authorities having a poor grasp of the issues. This is compounded by legislation, where additional clauses added to an earlier 'presumption' in the recently passed Standard in Scotland's Schools Bill mean that for some inclusion will continue to be discretionary, conditional and temporary.

Choice is limited - parents are offered a Hobson's choice - support in specialist centres or units or limited support within a restricted range of mainstream schools.

Where we see children included in pre-school, they and their parents face a continual fight to move on to the next stage, a fight that intensifies with progression. Numbers included fall successively between pre-school, primary, secondary and further education. Many mainstream survivors talk about their constant fear of being sent back.

Lack of forward planning mean that headteachers of many Secondary schools are simply unaware that a child with special needs is attending one of their feeder primary schools, leaving them ill prepared. Those within "special" schools often find themselves trapped within a system that sees them attending the same school from 5 through to 20, in mixed age classrooms. Options on leaving are limited with few entering full time paid employment.

In spite of these obvious shortcomings, the story is not all a bleak. Some authorities are pro - inclusive and are working with schools and parents to actively include children in mainstream classes and activities.

Where local authorities embrace inclusion fully, all pupils within the class benefit. Children exposed to difference from an early age grow up to be far more open-minded and tolerant when confronted with difference. Children learn to celebrate diversity.

Zarah began her educational journey at The Craighalbert Centre in Cumbernauld, a unit for children with special needs. By the end of primary 1, she had moved to her local mainstream school. Now in Primary 6, Zarah loves going to school, wearing the uniform and belonging to the school community. Zarah like any other 11-year-old, has many friends, has sleepovers and moans about homework.

Until last summer, David had split schooling. He would spend three days of his week at a special school for children with physical disabilities and the remainder of the week at his local mainstream school, alongside his brother and sister. His parents were increasingly concerned that he was falling behind children his own age.

One year on and David, now attends his local mainstream school fulltime. The change in David since this move has been considerable. He is a much happier and contented wee boy. He seems to be learning at a faster pace than before. More importantly he is an accepted member of his class and school community. David has never been teased or bullied.

Finally, Nina who is six and goes to her local mainstream school uses a wheelchair to get around and has speech difficulties. Her mum is convinced that mainstream schooling is the only choice for Nina.

*"Nina is in an ordinary class in a local school and she is simply getting on with being a six-year-old. Primary 2 has a pretty hectic schedule and, on top of reading, Heinemann mathematics, circle time and national tests, Nina has somehow to fit in occupational therapy, physiotherapy and speech therapy. How do we do that? It can be done only if the people who are involved are prepared to be creative, to work collaboratively with one another and to include parents fully in discussions.*

*I am pleased to say that, at present the two most important people in Nina's school life - her class teacher and her special needs auxiliary - are two of the most committed, thoughtful and resourceful people I have come across. They make inclusion work because they are willing to adapt what they do in the class and include Nina in absolutely everything.*

As someone labelled as having a physical disability, I was fortunate enough to attend a mainstream school; I have gone to University and am now settled in full time employment, able to enjoy life to the full. In my experiences, inclusion has been possible when parents, teachers, headteachers and local authority officials share a common belief that all children belong together. When all children are valued and included, the transition from child to adult is easier.

**Drew Hunter  
Scottish Human Services  
1A Washington Court  
Washington Lane  
Edinburgh EH11 2HA**

## Play, Leisure and Age-Appropriateness

Age-appropriateness is constantly highlighted as an area of concern in residential settings, day centres, secondary schools and at home. As Action for Leisure is about to publish an information leaflet on age-appropriateness, Nicola Burrows, AFL's Development Officer, explores some of the concerns and stories people share.

### *Case Study*

An older lady is visiting a leisure library in her local area. She has a learning disability but is able to make choices about things she likes and dislikes. On this day she chose a bumble ball - a brightly coloured plastic ball with bumps all over which, when you switch it on, vibrates or 'bumbles'. She had much enjoyment from the bumble ball and she wanted to take it back to her home to show the other residents. When she got home she shared the 'toy' she had borrowed. The staff were not very happy. They told her not to play with it and to take it back the next week. It was not appropriate.

- Is this an inappropriate activity for the woman?
- Should the staff stop her playing with the bumble ball?
- What are the factors that may make the activity appropriate or inappropriate?

These decisions are never easy and it is rare to find a definitive answer. This article hopes to offer some pointers and discussion points for work with young people and adults.

The issues surrounding age-appropriateness are not clear-cut. There with is no set of rules that say this is OK but this isn't. So often it is our own opinions and judgements that define what is and what is not age-appropriate. Even objectivity is tainted with our own experiences and ideas. More importantly, the people we make decisions for are rarely involved in the process.

The example above raises lots of questions, some people would agree with the staff, others would not. Let us look at some of the issues raised by the case study. Age-appropriateness must be influenced by various other factors. *What are the key issues?*

### **Rights and Choices**

To enable people to make an informed and 'age-appropriate' decision, they must be given a variety of appropriate choices and encouraged to try new options. New experiences can be frightening and/or peculiar the first time we try them we - must allow people time and space to explore new and adapted ideas.

There are also questions to be asked about the rights of individuals to choose something that interest them, and the right we have, as workers, to decide that a choice is not acceptable.

### **Control**

The choices we make enable us to have control over our life. Disabled people are often denied the opportunity to make choices and feel a lack of control. Play and leisure is an element of our lives that is defined by choosing when and what we want to do. Play and leisure time should aim to increase choice and control appropriately.

### *Case Study*

During a session in a residential unit a man kept on the periphery of the activities. He didn't join in, or even watch the other people using the equipment and interacting. This behaviour was not unusual. He spied a small police car that, once the driver was put in the seat, drove around with the siren whirring. The man followed the car around the room. He was fascinated. As the little car went past other people he pointed and waved them over to watch the car.

When the unit's staff came through they immediately picked up the car and told the man he could not watch the car any more. For the rest of the session the man sat in the corner of the room, he didn't join in any other activity or interact with anyone.

- What would you have done in this situation?
- What were the benefits of the man 'playing' with the toy car?

### **Place Appropriate**

There are certain things that are appropriate in certain places. We may have teddy bears on our bed at home but would not take the bear to the pub with us. There are some play and leisure activities (and equipment) that may feel uncomfortable in public, but what about in your own home? Age-appropriate decisions need to be set in this context. There are no easy answers, but it is often useful to ask what we are hoping to achieve. Play leisure and recreation can be powerful tools for developing communication, social interaction, focus, control and creativity.

As workers it is our responsibility to encourage the development of those skills, to enable people to have a positive experience. Age-appropriateness should be a tool to expand opportunity and choices, while respecting decisions.

Action for Leisure's new Information Leaflet, "Age-appropriateness - To infinity and beyond" explores the issues raised in this article in more detail. The leaflet costs £1.00 for subscribers, £1.25 to non-subscribers. To order copies please contact Action for Leisure.

**Nicola Burrows** Action for Leisure  
c/o Warwickshire College  
Moreton Morrell Centre  
Moreton Morrell  
Warks CV35 9BL

Tel: 019962 650195

### **Action for Leisure**

Action for Leisure is a small national charity working to promote play, leisure and recreation with and for disabled adults and children. At present we offer four main services:-

**Resource Centre** - containing equipment, toys, books, journals and videos. The Centre offers the opportunity to try out equipment before purchasing items from suppliers. It also offers guidance on equipment that may be suitable for individuals.

**Information Service** - offering information and advice about all aspects of play and leisure for disabled people.

**Outreach** - this includes training, stands at exhibitions, developing resources, partnership work

**'On my Doorstep'** - a new project to develop a database of local opportunities for disabled people across the country

A range of publications and posters are available to purchase and also a free Information Pack about the above services.

### **Subscription**

There is also an opportunity to receive regular updated information and other benefits by subscribing to Action for Leisure. Everyone who subscribes will receive three mailings a year and a discount on training fees and on our publications. Each mailing includes:

**Update** - full of information and news on:

- new play and leisure equipment, books, videos, posters, etc
- news about Action for Leisure
- details of the exhibitions where Action for Leisure will have a stand
- a special offer on some play and leisure items
- other items of interest

For further information, please contact:

**Action for Leisure**  
**Tel no: 01926 650195**  
**Fax no: 10926 650104**

# news....news.. ...news

## handseltrust - New initiative for parent support

A new organisation, the **Handsel Trust**, is being launched this autumn.

The Handsel Trust, a **UK-wide concern**, is registering as a charity and has already begun work to **focus attention on the need to offer support to parents of children with disabilities**. Far too many parents, throughout the UK, are left to cope alone, feeling abandoned and isolated, after disclosure of their child's disabilities. The Handsel Trust promotes a **keyworker model of support** (developed by the West Yorkshire initiative, One Hundred Hours).

The Handsel Trust is currently running a series of '**Speaking Up**' workshops for parents around the country, which enable parents to discuss how keyworking might benefit them in their own area. The Trust is also working on a piece of research, looking at parents' needs, and how they are or are not being met, across the country.

The Handsel Trust's launch event is the **New Opportunity Conference** to be held in Birmingham on **October 31st**. Parents and workers will be attending to discuss practical approaches to care co-ordination and keyworking within health, social services and education and will be joined by Professor Barry Carpenter, Chief Executive of Sunfield, and Dr. Tricia Sloper of the Social Policy Research Unit.

Peter Limbrick, Chair of the Handsel Trust, said:

*'The research has been done long ago; parents have pleaded for years for better support and for a co-ordinated service and practical projects like One Hundred Hours have shown the great benefits a keyworker brings to families. It is our aim now to help focus all of this information into a drive for better services for every family in the UK.'*

If you would like to find out more about the Handsel Trust and its work, please call **0121 4411580** or **0161 740 7757** for a copy of their new newsletter, *New Opportunity*, or visit their website at <http://website.lineone.net/~handsel>.

For information about the Handsel Trust, please contact:

Gudrun Limbrick-Spencer, The Handsel Trust, 83 Silver Street, Kings Heath, Birmingham B14 7QT  
Telephone/fax: 0121 4411580 Email: [handse@LineOne.net](mailto:handse@LineOne.net)

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## House of Commons Launch for RNIB Eye Care Campaign 25th October 2000

Yvette Cooper MP, Minister for Public Health will launch a new phase of RNIB's Access to Eye Care Campaign at a reception at the House of Commons on 25th October. The evening will be hosted by Roger Berry MP and will outline the urgent issues around adults with learning difficulties receiving high quality eye care.

RNIB is working to raise awareness of the importance of eye care for adults with learning difficulties - research has shown that 40% of the 1.2 million adults and children with learning difficulties have eye problems which are often unrecognised and only 47% get regular eye tests.

RNIB's Information and Practice Development Service on Multiple Disability works to improve the quality of life for adults over the age of 19 with visual and learning difficulties. It also aims to increase eye care for people who may be denied high quality health care.

For further information please contact Gill Levy or Sarah Barley at RNIB on 020 7388 1266.

***Enhancing Quality of Life:***  
a project to develop transitional programmes for people  
with profound and complex learning difficulties

**Summary and Extracts from Newsletter 2: September 2000**

There have been some important changes of project personnel since Newsletter 1:

Dr. Lani Florian, who was responsible for the project's survey of current provision (the results of which are summarised in this newsletter) is now Director of Education at MacIntyre, and has reduced her involvement. Dr. Helen Hayhoe has joined the project as research officer, while continuing to teach students with severe learning difficulties at Richmond upon Thames College. Professor Barry Carpenter, Chief Executive and Principal of Sunfield School, is now chair of the steering group in place of Philippa Russell who will continue on the steering group.

**Identifying case study sites for the action research phase**

Four case study sites have been selected for the action research phase of the project which is intended to consolidate and develop new ways of working and new opportunities for people with profound and multiple learning difficulties experiencing a variety of forms of transition in their lives. From a suggested list of 40 sites, a short list of 9 was identified and each site visited.

**Final Selection of four case study sites**

Four sites were selected all of which have agreed to work with the project during the action research phase. These four sites are:

- Bridge College, Stockport
- Springfield unit at Oaklands College of Further Education, Hertfordshire
- Creative Connections and Barnet College in north-east London working collaboratively
- A range of services in Oldham - various statutory and voluntary agencies, led by Training into Employment (TiE) working together.

**Characteristics of the case study sites**

The core characteristics for selection were:

- They were all recommended through more than one source.
- They all work with people with profound and complex learning difficulties as part of their core practice.
- Together they ensure geographical and demographic spread, and can sustain commitment to their work and the project in the long term.

In addition, there are contrasts between the different styles of provision in the sites. For example, taken together they:

- work with both school leavers and older adults in transition;
- use educational, adult services and other, more innovative, models for their practice;
- do work that is based in a range of situations - colleges, other institutions and the community;
- are managed by a mix of statutory and voluntary agencies;
- use a range of sources of funding to support their work with people with profound and complex learning difficulties.

These contrasts are seen as positive characteristics. The project will acknowledge and celebrate diversity rather than adopting a one-dimensional view of 'best practice'.

**Key characteristics of practice in the case study sites**

Key characteristics of the practice we have seen in our case study sites includes:

- interaction - between staff and students and between peers - it is highly valued;
- use of alternative and augmentative approaches to communication - signs, symbols, technological aids, objects of reference, photographs, real object cues, gesture, body language - to enable students to express preferences, identify members of staff, anticipate activities and follow routes around buildings;
- expertise by all staff in the use of communication systems, some of which may be highly individualistic and idiosyncratic;



- staff are highly sensitised to students' initiations, communicative behaviours and responses;
- staff have extensive repertoires of ways of working and can move flexibly from one approach to another, adjusting pace, style and challenge in response to signals from students;
- views and perceptions of students are regarded as central, and are acknowledged, respected and acted upon in practice;
- control is shared between staff and students - both in the teaching and learning situation and in planning and review phases;
- staff do not have diminished horizons for their students - strenuous efforts are made to use resources and to provide experiences which are age-appropriate, challenging and inclusive;
- effective collaboration between staff - teachers, therapists and support staff, from a number of agencies. Boundaries between roles do not inhibit practice, staff are able to work on a range of tasks in a range of situations; work is shared;
- staff respond to students holistically - distinctions between 'teaching' and 'therapy', 'support' or 'care' are minimised;
- ongoing commitment to staff development - which is shared and interdisciplinary;
- staff are reflective, analytical and self critical - they work together as problem-solving teams and are committed to the improvement of their practice - they are supported by managers who encourage them to work in innovative, exploratory ways.

These characteristics are already informing objectives for further development and these issues are helping to build a conceptual framework for our research.

A three part national survey of provision for pupils aged 14 and older who have profound and complex learning difficulties in England and Wales was carried out. A full report of the schools survey (part one) has been published in the September 2000 issue of the *British Journal of Special Education*. A report on the college survey (parts two and three) appears in the June edition of the *Skill Journal*.

#### **Transition destinations and college opportunities for pupils with profound and complex learning difficulties.**

Little is known about this group of learners as they move on in life when their secondary schooling concludes. What kinds of opportunities for further education are there? Are there other forms of provision? What are they? What options are currently available for pupils with profound and complex learning difficulties after they turn 16? In an attempt to answer these questions we conducted a three-part survey of schools and colleges in England and Wales.

A summary of the results of the three parts of the survey is given in the Newsletter. The concluding discussion of these results, showed that the schools survey found a gradual increase in the percentage of pupils who had the opportunity to participate in some kind of further education, as they grew older. This often began in the form of a school-college link scheme. However schools reported only 50 pupils moving on to residential specialist colleges at the end of the 1998-1999 school year whereas the specialist colleges reported enrolling 417 16-19 year olds in November 1999. It is possible that many of these students were not in their first year of college and that schools, therefore, would not have reported them. Or, it could be that those responding to the school survey did not differentiate between specialist and sector colleges. A third possibility may relate to differences in interpretations of the definition of profound and complex learning difficulties we adopted. For these reasons the data should be interpreted with caution as general indicators of patterns of provision rather than as absolute numbers of student placements and/or destinations.

Our purpose in conducting this study was to learn about range and type of current provision in order to prepare for and inform subsequent phases of our project. This survey has been concerned with establishing a better understanding of range and type of college provision for students with profound and complex learning difficulties, and as such has not addressed issues of quality. In the next phase of this project we plan to address these issues of life's quality directly by working with practitioners to develop a curriculum framework and materials which we hope will facilitate the process of transition from school to adult life.

If you want further information about the project please contact,  
Peggy Nunn, University of Cambridge School of Education, Shaftesbury Road, Cambridge CB2 2BX  
email: pln20@hermes.cam.ac.uk

# *report back .....*

## **FORUM ON LEARNING DISABILITY Therapy in Schools: Problems, Policies and Good Practice**

This conference was held on 4th July at the Royal Society of Medicine and was very well attended by representatives from education and the therapy services.

The conference was opened by Professor James Hogg, who introduced the Learning Disabilities Forum which recognises the multidisciplinary aspect of health care. For 15 years, the Forum has organised 4 conferences a year to draw in a wide range of representatives from the whole range of professions and services, including parents, and family carers.

In the introduction, Dr. Nicola Grove said that the conference was intended to name and address problems and issues relating to therapy in schools. She emphasised the importance of analysing these and identifying strategies to deal with them, and to develop and disseminate innovative practices.

### **Developing a policy framework for therapy in schools**

#### **Dr. Hilaire Williams and Julia Ritchie**

Dr. Williams gave a brief overview of government policy and guidance in relation to identification, assessment and meeting of special educational needs in the '90s and the Programme of Action (1998). She spoke of the key themes of:

- high expectations - the National Literacy Strategy, National Numeracy Strategy; Target setting, early Years Development and Childcare Plans, Educational Development Plans, Sure start;
- supporting parents;
- inclusion where parents want it and where support can be provided;
- practical support - revision of the Code of Practice; provision of resources;
- professional development - training for teachers (TTA Core and Extension standards for knowledge, understanding and Skills) and funding to increase training for LSAs;
- promoting partnership locally, regional and nationally

Julia Ritchie described the work of the joint DfEE and DoH working group on provision of speech and language therapy services to children with special educational needs. She described two models of therapy: direct or consultative, and questioned the management of speech and language therapy services - by Health or Education?

Pilot projects for new practices have been set up and recommendations arising from these will be published and will be relevant to all therapy services. New practices should be encouraged by the Health Act 1999 which is intended to improve interagency and joint working, and include user views. Pooled budgets will make critical the consultation and complaints procedures, decision making, quality assurance, best value, inspection arrangements. An example in Kent is the Partnership Board with both health and education budgets, and with representatives from health and education and parents.

### **Therapy in schools: issues in service delivery**

#### **Dr. Philippa Russell**

Dr. Russell focused on the provision of speech and language therapy - "a scarce as well as a highly valued resource." She noted that interventions are most effective if carried out within schools, and described an number of roles which SLTs could expect in the future. These included assessment, diagnosis and therapy in collaboration with schools and families; providing curriculum support to schools, particularly the use of language in classroom settings; providing support and training for teachers and LSAs in all aspects of language; contributing to the school's and LEA's development planning and encouraging closer partnerships between health and education.

Dr. Russell described the dilemma of what is 'educational' and what is 'not educational'. She spoke of two decades of debate about the optimum method of delivery (direct or consultant), the responsibilities of health and education authorities to commission appropriate levels of services. How to develop good working partnerships between therapy and education and who delivers what - teachers and assistants as co-therapists; the level of service and parents' role in supporting speech and language programmes in school. She noted that parents typically prefer direct delivery in individual sessions for their child.

She described a number of ways forward:

- Change in the delivery of SLT services - the SLT as consultant;
- Schools as purchasers of SLT services - different ways of providing therapy services;
- Common training for teachers and SLTs about early language acquisition, identification of difficulties, teaching style and curriculum outcomes;
- Strategic approach to building communication and language skills across the curriculum. The importance of special schools in developing this in mainstream settings;
- Accepting the challenge of inclusion, with its implications for training and specialist, advisory and therapeutic help in different settings;
- Educational teams - teachers and LSAs to be co-workers with consultant therapists;
- Enhanced role for assistants including administration arrangements, liaising with parents, helping pupils with therapy tasks, and contributing to the Annual Review;
- Increased management role for SLT (eg. feeding management);
- A curriculum-based approach to communication, speech and language. Is there a place for a new National Speech, Language and Communication Strategy for schools?

### **Education and Health: key issues in collaboration**

#### **Dr. Elspeth McCartney**

Dr. McCartney described Health and Education as "two large and powerful public services, with separate functions, structures and processes" operating within a systems environment - the context of the community and larger society in which the services is situated. To facilitate collaboration these differences must be appreciated.

Dr. McCartney described a number of ways in each aspect of the service system in which difficulties could arise in working with other services. Therapists are used to multidisciplinary working and being 'experts', they are less used to planning together whereas teachers are inexperienced in working with other services. She suggested that for collaborative working there was a need for both compliance - recognising the contributions of others, and co-operation - involving trust, mutual respect and support, joint planning and egalitarian relationships.

Needs are conceptualised in different ways - medical (intrinsic to the child) or educational (intrinsic to the environment). These should be complementary. Health works on a priorities system, whereas education must provide for all. It is difficult to find prioritising criteria which are both educationally and therapeutically valid, and the shortage of therapists makes medical prioritising more likely.

Dr. McCartney identified a need to plan the workforce, and to identify the number of therapists needed, to establish joint funding and exactly what the funding should cover.

### **Parent issues and parent partnerships**

#### **Amanda Roberts**

Amanda Roberts emphasised the importance of first meetings - the verbal and body language, and the interest taken in the child. She described the subtleties involved in communication between parents and professionals which can make it difficult to establish common understanding and pointed out that parents are often confronted with a 'panel' of professionals, but with good communication skills and appreciation of each other's perspective, these meetings can become valuable.

She went on to describe the Parent Partnership Network in Devon and Cornwall, which brings together everyone that is involved with the child and helps to form a partnership where everyone contributes and feels a valued member of the partnership.

Experience has shown that there are key areas which can cause discord: therapists are frustrated when programmes are not continued at home or at school; parents are frustrated when they are not carried out at school, or they feel unable to carry out programmes or strategies themselves because of the demands of the rest of the family.

She suggested that good communication can overcome these problems - parents need to listen to professionals and need to be listened to by professionals. If opinions are listened to and considered, a better level of communication should result.

### ***Panel Discussion***

A panel of the morning speakers responded to a number of questions put by the participants: Financing speech and language therapy in schools - the SLT working Group needs to report and give recommendations. Money hypothecated to education services to purchase SLT services. Problems of retention of SLTs and numbers in training. Issues of pay and conditions - therapists going into the private sector.

Physiotherapy - not in the school curriculum which leads to resistance. Major training is needed for teachers in this area. Manual handling still creates barriers to inclusion. Denial of some curricular and leisure activities has resulted from the Manual Handling Regulations. Need to identify good and safe practice. Concerns about continuity of care, and preventative care.

Special Educational Needs Disability Rights in Education Bill - delay in publishing. Timing in regard to the new Code of Practice.

### **Current Practice and ways forward in Occupational Therapy, Physiotherapy and Speech and Language Therapy**

**Felicity McElderry, Marie Gascoigne and Stephanie Cawker.**

**Marie Gascoigne** described this session as focusing on identifying models of good practice in therapy in educational settings. She went on to discuss issues in relation to the provision of speech and language therapy.

She described the context for therapy as being both driving forces: legislation, inclusion, disability awareness, parental choice, emerging examples of good practice; and restraining forces: funding anomalies, training needs, increased demands on educators, parental choice (needs to be informed) structures and language of services, professional threat.

She suggested that a prescribed model of good practice was not needed as the Scoping Study shows a variety of good practice. She asked "how do we know what is good practice?" She suggested that it should provide a range of interventions, be child centred and flexible, appropriately researched and at an effective level and she asked whether collaboration would end therapy as we now know it.

She discussed three levels of intervention: direct, indirect and advisory. It might be within the classroom or away from the classroom (planning); it might be individual or with others. She emphasised the importance of skilled practitioners, with different levels of training.

The IEP could serve as a vehicle for collaboration. Joint setting of targets and flexible strategies across a range of interventions would help to ensure that therapy was child centred. Various monitoring mechanisms could be in place. She emphasised that the outcome measures need to be appropriate to the child and to the setting.

Finally, she suggested the way forward might include: clear government policy and legislation; models of good practice based on evidence; consistency in the services.

She concluded by saying that therapists should be confident of their specific skills and able to identify the competencies shared with other professionals. They should be creative in meeting individual needs - "It's amazing what you can achieve if you don't take the credit!"

**Felicity McElderry** stated that the Education Acts have made a major impact on the demand for paediatric occupational therapy. She described the challenge of responding to individual needs of all children in every setting, and maximising the potential for learning. OTs are involved with physical, intellectual and mental health needs.

She gave examples of good practice in terms of providing equipment, advice on positioning, prevention of deformity, promoting living skills and hand function, providing training for governors, teachers, assistants on topics identified by the school staff. She noted that OT draws together health and education, and can bridge the home school divide.

Because provision of OT is more limited than speech and language therapy a teamwork approach in assessment and practice is necessary. She suggested that senior practitioners should act as consultants, and transfer skills to the whole staff, with the therapy aims being translated into the classroom and monitored by the therapist.

OFSTED inspections tended to ignore therapy, and there is a need for understanding of each other's expertise, and of evaluating effectiveness. A common language for parents, teachers and therapists would help to identify and define important targets.

*Stephanie Cawker* described some common dilemmas in physiotherapy provision. She pointed out that physiotherapy was there for the child, not for the school which should support the therapist.

Some of the difficulties faced by physiotherapists include: blanket referrals, recommendations on statements, balancing a two tier service, geographical problems, funding of equipment. She emphasised the importance of sharing of skills, and of training in schools.

She described the treatment versus management issue: treatment is detached from home and classroom, is therapist orientated and exercise and task orientated. Management is carried out in the normal situation, is ongoing, and includes the advantages and limitations of the situation. The therapist is advisor and catalyst for the actions and attitudes of others, and aims are function orientated.

Difficulties arise because some families are not looking for a management model, and physiotherapists may be resisted in the classroom making management difficult.

Finally, she identified some essentials of physiotherapy: prevention of pain and deformity, posture, help using aids, seating, adaptations.

### **Therapy and the school curriculum: developing an inclusive framework**

#### **Nick Peacey**

Nick Peacey examined the revised National Curriculum and other national initiatives such as the National Literacy and Numeracy strategies and the Key Stage 3 (11-14) initiative.

He described the main changes as being: a more explicit rationale for the school curriculum; a more inclusive curriculum framework; a less prescriptive and more flexible national curriculum; a framework for Personal Social Health Education (PSHE) and citizenship at Key Stages 1-4; and language across the curriculum.

When considering inclusion, he first posed the question - does individual planning mean individual teaching? He went on to say that the curriculum should take account of the different experiences, strengths and needs of all children, and focus on diversity, including race, gender and disability. Effective learning environments would ensure equality of opportunity for learning through resources to support access, appropriate targets and teaching approaches.

He described the PSHE curriculum as being concerned with the health and wellbeing of everyone in the school.

Threads for development included: a commitment to therapy within the curriculum, and to validate therapy as part of the school curriculum.

### **Panel Discussion**

The final panel discussion covered the following topics and comments:

- End of Key State assessment and exams are contradictory in terms of inclusion.
- Children's mental health issues are often ignored or overlooked. Schools need more resources and support to help pupils. There is a need for protocols for moving forward in this area.
- If the National Curriculum is not made more 'forgiving' to pupils with complex needs, were are not including them.
- There is a need to be much more flexible in school times to incorporate priority needs and fit other things around them.

**Nicola Grove** drew the conference to a close with the comment that problems have been aired and named, although it is not possible to answer all of them. A book of the papers arising from the Conference will be available in due course.

## **PIMD SEMINAR 24th May 2000**

### **'People with Profound and Multiple Disabilities Get Older Too'**

#### **Getting Older in Modern Society - with or without intellectual disabilities.**

Professor James Hogg was the opening speaker at this seminar and he introduced the topic by speaking about the issue of ageing across the world. The United Nations Resolution 45/91 summarises the principles that should guide the way that we treat older members of society. These principles of: Independence; Participation; Care; Self-fulfilment; Dignity are familiar to anyone working in the field of learning disability.

He spoke of the increasing amount of literature on the subject of ageing and learning disabilities which, however, makes little reference to people with PIMD. He pointed out that despite a considerably reduced life expectation, people with PIMD do live into adult life, and age related needs must be considered as for the wider population.

The issues raised and discussed by Professor Hogg included:

- The nature of ageing as a lifelong process involving three types of ageing: chronological, social and biological.
- Older people with intellectual disabilities - improvements in medical provision increasing the life expectancy of people with PIMD (current average is 25 years) and the management of age related disorders.
- Family care and caregiving - satisfaction and stress are involved, but ageing both of the caregiver and adult child creates an additional burden of care. Service responses are often insufficiently tailored to individual need, or fail to appreciate the nature of long term family caregiving. There are cultural differences in attitude to care, and limited research on this. Carers tend to be reluctant to plan for the future. The person being cared for also contributes to the family - giving a sense of purpose. Aspirations for the future for people with PIMD - how do we facilitate choice. The importance of the social and economic context in the well being of carers.
- Residential considerations - older people with learning disabilities often lead residentially unstable lives as a result of changing policies and difficulties in continuing caregiving. All options should be open to people with PIMD, and appropriate support should be given. Where there are additional needs e.g. dementia, mental health problems or physical decline, decisions should be based on meeting needs, not automatic transitions into congregate nursing homes.
- An inclusive community - People with PIMD are disadvantaged in the type of residential provision available which is typically related to the ability of the person. Friendship networks tend to be restricted to staff and family members. People with PIMD are less likely to be involved in domestic and inclusive leisure pursuits and older people are more likely to receive centre based day service provision. Some hard thinking needs to be done to determine the most appropriate models of day service provision for people with PIMD to take into account their high medical needs. The concept of retirement for unemployed people or those with PIMD is ambiguous, and may be used for administrative convenience.

Professor Hogg drew attention to two particular issues: ageing in women with learning disabilities with respect to health care needs and aspirations specific to their gender; and the number of people over 60 from ethnic minorities, now small, but increasing, and likely to do so more rapidly in 20 years time.

He concluded by saying

- "Increased longevity and a gradual rising population in themselves are not what has led to the intense concern with older people with intellectual disabilities that I have illustrated.
- This has arisen because historically we have segregated people from the mainstream of their peers and continue to do so.
- Increasing inclusion and needs led approach will lead to their assimilation into the policies and processes that are being developed to meet the needs of the older population generally.

For people with PIMD, whilst the average age is 20-25 years currently there is every expectation that they will be living to 'a ripe old age.'

#### **A Parent's Perspective - Jean Willson**

Jean introduced her 30 year old daughter, Victoria, who has profound and multiple disabilities. She painted a vivid picture of Victoria, and then recounted the battles which she has fought to enable Victoria to achieve 'a home of her own.' She described the purpose built bungalow which Victoria shares with her friend, Lisa (who also has high support needs), and the support she receives.

Although Jean said that not all her needs are well supported, (for example, her mental health needs are not recognised) overall the house is a success, with a consistent, stable staff team working to Victoria's Community Care Plan and a good system for accountability. She has a good social life, gets out into the local community, and has two days of 'flexible day service'.

### ***Planning for the Future***

Jean and her husband are now planning positively for her future without them, and Jean has had to learn to delegate, which was extremely difficult because of a history of things going wrong in the past when Victoria was in residential provision. Victoria now has a 'Circle of Support' of 5 women, who have varied and different attitudes, and challenge Jean's views. Jean has also set up a discretionary trust. They are slowly relinquishing their role to others as they plan for their own retirement and Victoria's future.

Jean identified a number of important issues:

- The need for equity of access to health services;
- The importance of listening to parents and the person with a disability;
- The importance of the development of the knowledge, skills and attitudes of staff who work with Victoria and Lisa;
- Staff attitudes and communication;
- Working together - the need for real multi-professional co-operation;
- All training should include the disabled person and their carer;
- Include others in son's/daughter's life;
- Encourage, support and delegate responsibility to advocates at every stage;
- Set up a discretionary trust, with trustees aware of their roles.

She concluded by saying that Victoria is now making choices they never dreamed of. Her gifts are a passion for music, food, people watching and laughter!

### **A Service Response to Getting Older - John Harris**

John opened his session by saying that his presentation would pose more questions than answers. A number of discussion points emerged:

- Expectations - families are frequently given poor advice (for example, poor life expectancy of the child with PIMD) which clearly shapes planning for the future.
- Transition from school to adulthood is socially imposed and is based on age, not on ability. It is not well organised, especially for young people with PIMD.
- Closure of day services - the current trend to close adult training centres, and replacement by colleges often leaves parents with the burden of care. Basic needs, such as transport, can be overlooked. Substantial services are needed in place of traditional day services for example, in Coventry a physical centre provides a core service for people with PIMD who are out at least 50% of the time.
- Leisure - a need for creativity and imagination to ensure that people with PIMD can be involved.
- Employment - how realistic is this for people with PIMD?
- Joint planning - is there a way of enabling the planning process to work? Will real joint work ever fully evolve? It can look good on paper, but not happen in reality.
- Sex and relationships - dismissal of sexual feelings and people with PIMD. Can be a source of tension between parents and workers. There is a need to acknowledge sexuality and consider how to make relationships meaningful and safe. Physical needs can place a big demand on 'friendship'.
- Age appropriate activities - How do we offer new opportunities, and not just take things away? How do we avoid infantile environments, and yet meet therapeutic needs?
- Health - access to good health relies on carers and the ability of the individual to communicate. There is a need for better training for health professionals. For example, there is a national group on dentistry that has had to fight hard for the inclusion of people with PIMD.

### ***Longer term issues***

Many people with learning disability have 'an unmarked life'. Peter Lazlett talks of 'the third age', the point in life when obligations have gone and when we may reach a point of personal discovery. Lazlett argues that the third age can happen all our lives.

How do we address the issue of personal development in people with PIMD?  
How do we meet the challenge of personal development across 30 years?

# reviews ... reviews ... reviews ... reviews

*Unlocking the Future. Developing new lifestyles with people who have complex disabilities*

Edited by Barbara McIntosh and Andrea Whittaker.  
Kings Fund. Ndt 2000.

*Unlocking the Future* is the last book in the Changing Days series, focusing on people with learning disabilities and high support needs. As opportunities rightly continue to expand for their more able peer group, the needs of people with complex disabilities often appear to be neglected. This is therefore a very welcome conclusion to this excellent series.

This is a practical and thought provoking book aimed at managers, commissioner, providers and anyone who is responsible for developing day opportunities. However much of its content will be highly useful and relevant to anyone involved in supporting people with high support needs to improve their lives.

The book starts with an easy to read summary of the main text, made more accessible with larger text and symbols and ends with a Personal Planning Book designed to be photocopied. Each chapter focuses on specific areas such as communication, supported employment and inclusive leisure, and moves on to discuss how to manage and finance the far-reaching changes to day services that are advocated.

The book acknowledges the complexity and skill necessary to get to know someone with complex disabilities well enough to understand how he or she relates to the world. It is only from this starting point that we can begin to plan meaningful day opportunities. Communication is a very important part of this process and there is an excellent chapter that provides an in-depth approach toward developing this.

The chapters on Person Centered Planning and the use of planning circles demonstrate how a person centred approach can be used to effect real change and extend opportunities for people whose needs are often regarded within services as too difficult or too expensive to meet. The chapter on employment served to challenge the common assumption that people with high support needs cannot work, providing real life examples of situations where this has been achieved.

The book does not minimise the challenge of working with people with high support needs, rather it acknowledges that we have all much to learn about doing so - "Say you don't know how to do something yet, rather than someone can't work".

**Beverley Dawkins**  
National Officer (PIMD)  
MENCAP

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## RESOURCES

### JOURNALS

*Journal of Research in Special Educational Needs* - a new journal focusing on research in special education. Editor: Dr. Lani Florian, published by National Association for Special Educational Needs (NASEN). First issue March 2001. For further information telephone 01827 311500; email [welcome@nasen.org.uk](mailto:welcome@nasen.org.uk); website [www.nasen.org.uk](http://www.nasen.org.uk)



## NEW BOOKS

*See What I Mean: Guidelines to Aid understanding of communication by people with severe and profound learning disabilities.* by Nicola Grove published by BILD Publications in Association with MENCAP 2000.

*Unseen and Forgotten: Equal access to optometry services for people confined to home* by Lynne Nicholl and Karen Hodgson. Published by RNIB 2000

*The Education of Children with Medical Conditions* edited by Alison Closs, published by David Fulton Publishers 1999

*Learning Disabilities and the Family: The Young Child with a Learning Disability and Learning Disabilities and the Family: the teenager with severe learning disabilities.*  
Available free from Mental Health Foundation. Jowyn Jenson: 0207 535 7420

New Teenage Titles from Bag Books: *The Match, First Day, It's cold INSIDE!*  
First young adult title: *Last Bus Home*  
Available from: Bag Books, 0200 7358 4021/email: bagbooks@appleonline.net

*Focus Factsheet - Eye drops for adults with learning difficulties.* Available from Sarah Barley, RNIB, 224 Great Portland Street, London W1N 6AA

*Getting your Eyes Tested and Getting New Glasses* - two illustrated booklets and audio tapes giving information on what is involved in visiting an optometrist for an eye test and choosing and caring for a new pair of glasses. Published by RNIB Customer Services 0845 702 3153

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## COURSES AND CONFERENCES

### NOVEMBER

#### 16th Make your Mark - Gallery-Based Workshops

These ninety minute workshops can be adapted to the needs of a wide range of groups including those with special needs. The emphasis is on using practical activities to explore works on display such as markmaking, drawing with wire or simple movement tasks. Choose your theme from : Space, Relationships, Feelings, Symbols, or Construction.

Organised by: Tate Britain  
Venue: Tate Britain, Millbank, London  
Further details: Tate Box Office  
02007 887 8888

#### 16th and Circles of Support - Getting Started

Two day training event to enable participants to explore how to develop a 17th natural support network around people who are isolated or excluded from typical everyday relationships.

Organised by: Circles Network  
Leaders: Christine Burke, Simon Goldsmith, Mark Williams  
Venue: London  
Further details: Circles Network  
0117 939 3917  
email: frances@circlesnetwork.org.uk

#### Week beginning 20th November

#### Gentle Teaching with people with learning disabilities, especially those who may challenge

Leader: John McGee  
Organised by: roc  
Venue: Cross Street Centre, St. Albans  
Further details: roc  
Tel: 01923 663628

21st and 22nd Cultural Issues in Sexuality Work with People with Learning Disabilities  
Organised by: Consent  
Leader: Seema Malhotra  
Venue: Harperbury and Brent  
Further details: Consent  
01923 670793  
cnsent@hnhsroc.demon.co.uk

25th Action for Leisure Resource Centre Open Day  
Multisensory room; Items to purchase; Wide selection of toys, games and equipment; Database of information; Reference library of books, videos, journals and publications. Fully accessible resource centre with disabled access parking and toilet. Refreshments and other facilities nearby including farm and garden centre.

29th to 30th Independent Living 2000  
Products and free seminars  
Venue: Wembley  
Further details: Independent Living  
Tel: 01275 836465

## DECEMBER

5th and 6th Exploring Sexuality in working with People with Profound Learning Disabilities

The course aims to impart information on research in this field and allow staff to examine implications within their practice.  
Organised by: Consent  
Leader: Christina Paparestis  
Venue: Harperbury  
Further details: Consent  
01923 670793  
cnsent@hnhsroc.demon.co.uk

6th Make your Mark - Gallery-Based Workshops  
These ninety minute workshops can be adapted to the needs of a wide range of groups including those with special needs. The emphasis is on using practical activities to explore works on display such as markmaking, drawing with wire or simple movement tasks. Choose your theme from : Space, Relationships, Feelings, Symbols, or Construction.  
Organised by: Tate Britain  
Venue: Tate Britain, Millbank, London  
Further details: Tate Box Office  
02007 887 8888

7th Seven Ages: Transition and Support in the Lives of People with Intellectual Disabilities

This conference is concerned with the life-span development of people with learning disabilities and the importance of transitions from birth through to death. International speakers.  
Organised by: Forum on Learning Disability  
Venue: Royal Society of Medicine  
Further details: Deborah Johns  
tel: 020 7290 2984  
email: deborah.johns@roysocmed.ac.uk

7th Massage  
Learn basic massage techniques to arms, hands, neck and shoulders and more.  
Organised by: Circles Network  
Leaders: Berni Coffin and Nicola Frewin  
Venue: Bristol  
Further details: Circles Network  
0117 939 3917  
email: frances@circlesnetwork.org.uk

31st Support for Female Carers/Mothers of People with Learning Disabilities  
Specifically for mothers and female carers to explore what issues arise for them, how they can support their daughters or sons and how and where they get support themselves.  
Organised by: Consent  
Leader: Christina Paparestis  
Venue: Harperbury and Brent  
Further details: Consent  
01923 670793  
cnsent@hnhsroc.demon.co.uk

## JANUARY 2001

29th An Introduction: Issues Relating to Mental Health and People with Learning and Disabilities  
30th Participants will explore reasons why people with learning disabilities are perhaps more prone to mental health issues. Introduction to mental health conditions.  
Organised by: roc  
Venue: to be confirmed  
Further details: roc  
01923 663628

15th and 16th Aromatherapy for People with Learning Disabilities  
History of aromatherapy, therapeutic properties of essential oils with practical exercises including massage.  
Organised by: roc  
Venue: to be confirmed  
Further details: roc  
01923 663628

## FEBRUARY

26th and 27th Working with People with Profound and Complex Disabilities  
Introductory course for direct support staff who work with adults with profound disabilities. Looking at the emotional, physical, spiritual, social and intellectual needs of people with a view to generating ideas for new ways of working.  
Organised by: roc  
Venue: to be confirmed  
Further details: roc  
01923 663628

13th and 14th Cultural Issues in Sexuality Work with People with Learning Disabilities  
Organised by: Consent  
Leader: Seema Malhotra  
Venue: Brent  
Further details: Consent  
01923 670793  
cnsent@hnhsroc.demon.co.uk

21st Managers Responsibilities in Sexuality Work  
To enable managers to consider their role, what support they may need and what support they may need to offer to their staff.  
Organised by: Consent  
Leader: Mike Hobson  
Venue: Harperbury  
Further details: Consent  
01923 670793  
cnsent@hnhsroc.demon.co.uk

## **LEARNING PACKS**

### Choice Discovered

A training pack for frontline staff, volunteers, carers and advocates supporting people with severe learning disabilities who have little or no speech. The training can be run over one full day, or over three two-hour sessions. The pack includes guidance notes for a facilitator and student worksheets together with a video. The training includes practical exercises in communication skills, and examines the different ways in which people with profound learning disabilities communicate with others.

Available from the Foundation for People with Learning Disabilities, 20/21 Cornwall Terrace, London NW1 4QL. Tel: 020 7535 7441.

### Pathways to Citizen Advocacy

A set of 16 Units for use by citizen advocacy groups in preparing ordinary citizen to establish and build advocacy partnerships with people who have severe learning disabilities.

Produced by a BILD project supported by the Foundation for People with Learning Disabilities and the Home Farm Trust.

For further details contact BILD Distance Learning Department Tel: 01562 852942

### Better Health: Improving Health Promotion and Health Care for People with a Learning Disability

An new independent study pack produced by BILD. The pack comprises a set of six units on the following topics: Introduction to Health Care; Finding out about illness; Treatment; Health Promotion; Overcoming Inequalities in Health Care; Ill Health and Learning Disability.

Available from BILD Publications, Plymbridge Distributors, Estover Road, Plymouth, PL6 7PD Tel: 01752 202301

## **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 four levels: Post experience certificate (level 1), Advanced Certificate (level 3), Post graduate diploma and Masters (level M)

University of Birmingham School of Education in conjunction with BILD

Further details: Linda Scott, tel: 0121 414 3466

### bild Distance Learning Programme

These courses are aimed at direct care staff and first line managers working with children and adults with a learning disability. Accredited through the Open College Network at Level 2 or Level 3.

Eligibility for BTEC Intermediate or BTEC Advanced Award: Working with People with a Learning Disability.

Courses include:

Positive Approaches to Challenging Behaviour

Ageing Matters: Pathways for Older People with a Learning Disability

Better Choices - Fuller Lives: Working with People with Profound Learning

Disability and Complex Support Needs

Better Health: Improving Health Promotion and Health care for People with a Learning Disability

Further details: Tracey Tindell

Tel: 01562 850251 e-mail: tracey@bild-res.demon.co.uk

or Lelsey Barcham

Tel: 01562 852942

## ***FUTURE FOCUS .....Health Issues***

The theme for the next issue of PMLD-Link is 'Health Issues'. Under this broad title we want to include information on topics as diverse as oral health care, continence management, experiences of using acute hospital services, epilepsy and its management, healthy eating and adapted physical activities.

**Accessing services:** People with learning disabilities should have the same right to equal standards of healthcare as the general population. However, there is evidence that they experience poorer health, have many unmet health needs and have a much lower uptake of screening services than those without disabilities (Whitfield et al 1996 and Band 1998). While the oral health needs of people with learning disabilities are similar to the wider population, the additional health problems experienced by people with PMLD, together with the side effects of medications such as anti-epilepsy drugs, can result in additional dental problems. This, coupled with the fact that many can only access dental treatment under sedation or general anaesthesia highlights the need for preventive oral health measures to be seen as a high priority.

***Please tell us of your experiences in accessing screening programmes***

***Let us know how you implement oral healthcare programmes for people with PMLD.***

**Healthy eating and lifestyles:** We are all constantly being told that we need to improve our health, lead more active lives, eat more fruit and fibre, loose - in some cases - gain weight. This is not easy when you consider how dependent most of us are on cars to get from A to B, the length of our working day and how much more convenient it is to have a ready cooked meal than having to cook fresh fruit and vegetables each day. Just think how much more difficult it is for people with profound and multiple learning disabilities and their parents and carers to follow healthy lifestyle advice. How can you have the recommended five portions of fruit, and enough fibre and fluid each day if your diet is only semi-solid or if you are fed non-orally?

In addition to their physical disabilities, many people with profound learning disabilities will also have severe respiratory problems which inhibit their opportunities to participate in any physical activities. Keep fit gurus do not design their programmes around a person who is a wheelchair user. We are increasingly hearing of people with profound disabilities being denied access to services aimed at prevention, such as screening, well-women clinics and to community leisure facilities. Despite this rather gloomy picture, we know that parents, carers and professionals have developed many innovatory ways to improve the health of the people for whom they care and to ensure that they do gain access to health and leisure services which are central to a healthy life.

***Tell us about experiences you have had with respect to accessing health services, both good and bad.***

***Information on projects around keep-fit, healthy eating or health care prevention initiatives would be most welcome.***

**Women's healthcare:** The health of women with profound disabilities is a most neglected area and we are particularly interested in sharing information on ways and means of involving girls and women in health education programmes. The adult status of women with learning disabilities and particularly those with PMLD is often not recognised (Burns 1993). This in turn leads to their specific healthcare needs being ignored or not being seen as a high priority. This trend is being addressed by a number of enlightened professionals, and we are beginning to see some very useful

materials around this topic being made available. The fact that the WHO have recently published a booklet on women's health as part of their series on ageing and learning disabilities illustrates the importance of this topic.

***Information on health education programmes for women with profound learning disabilities would be of great interest.***

***Details of training materials or projects specifically on the topic of understanding and management of menstruation would be welcome***

**Assessing pain:** *Lastly, but by no means least we need to look at the whole issue of identifying or assessing pain. There are some references to this in the literature but in the main this is highlighting the difficulties rather than coming up with solutions or guidelines. Please let us have information on any projects around this topic. We would also be very interested to hear about any research that is on-going or have details of materials or publications on 'pain assessment'.*

*The whole idea behind concentrating on 'health issues' is to share information and to learn about good practice.*

**Loretto Lambe, *pamis* Director**  
White Top Research Unit  
Frankland Building  
The University  
Dundee DD1 4HN

#### **References**

Band, R. (1998) *The NHS - Health for All?* London: Mencap

Burns, J. (1993) Invisible women - women who have learning disabilities. *The Psychologist: Bulletin of the British Psychological Society.* 6, 102-105.

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Whitfield, M., Langan, J. and Russell, O. (1996) Assessing general practitioners' care of adult patients with a learning disability: case-control study. *Quality in Care* 5 31-35