PMLD LINK

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

Summer 2006

Early Years

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Vol 18 No. 2 Issue 54

PMLD-Link is an informal journal for practitioners and carers working with people with profound and multiple learning disabilities (PMLD), of all ages and in all situations. It is published three times a year and covers a wide range of issues of interest and practical use in the day-to-day work of practitioners, parents and carers in schools, colleges, adult provision, in the home, and many other settings. In recent years the scope of the articles has been widened to include all professions and services, and to cover issues pertaining to all groups, including occasional articles by practitioners and parents from overseas.

PMLD-Link is a grass roots publication and depends on written contributions from parents and carers, teachers, psychologists, special support assistants and workers in all settings. The contributions may be:

- short papers
- news of individuals, families or other groups
- information sharing
- requests from readers for information or useful addresses

PMLD-Link also includes:

- information and reviews of resources or publications and reports on conferences and research
- listings of courses and events relevant to the area of PMLD.

It enables readers to create networks, and provides a forum for contact with others involved in the field.

The editorial team is drawn from a variety of settings and currently includes:

There is also a consultation group to assist in commissioning articles from all regions of the UK and overseas and, to ensure a wide coverage of topics. The administrator of ***PMLD-Link*** is Paul Bramble, The University of Northampton, e-mail: paul.bramble@northampton.ac.uk

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

Early Years

Articles

GUEST EDITORIAL
Summer 2006

Early Years

This summer issue celebrates Early Years. Never before has there been so much interest in early years and the importance of early intervention with babies and young children who have special needs. With the amazing advances in medical interventions, access to MRI scanning, we now have the clinical evidence to support long held theories that intervention in the earliest stages of life can have major beneficial effects for future learning and well being.

When my own daughter Victoria was born 23 years ago this summer, she was born into a very different world. There was very little support around for families and if you had access to a supportive Child Development Centre and health visitor you were very lucky indeed.

The views held by many health professionals at that time were very negative and I know that from listening to some of the things which were said to us I was not encouraged to expect too much! Twenty years or so on we are now in the midst of a very different time of change and development for Early Years.
As an Early Years advisor for a local authority I often struggle to keep up with the amount of new documentation generated by the DFES Sure Start unit. However, the recent Early Years Foundation Stage document (draft consultation) is very welcome.

It is intended to bring together into a single quality framework, care standards, learning, and development for children in all early years settings from birth to the august after their fifth birthday. It will play a vital role in improving the life chances for all children.

This edition has a varied collection of articles, which gives a picture of some of the initiatives happening around the country. I have included a very moving article submitted by a wonderful parent who bravely shares with us her story of the aftermath of Tilly being diagnosed.

We have news of the early support materials and an informative article about the work of Portage today.
I would like to extend a very big thank you to everyone who has contributes to this edition. Enjoy!

Julia Dixon
Guest editor

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Articles, News, Reports, Letters
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Articles, News, Reports, Letters
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Adult Years

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Future Focus:

Changing Perspectives

By

Alice Bradley

I'm new to the editorial team – though not to **PMLD Link** – and what better introduction than to be invited to be guest editor for the next edition, a request I'm delighted to accept. The somewhat loosely focused title above signals our intention to give our next edition a general or 'open' theme and to do this once a year. There are several reasons for this. It provides more opportunities for contributors to give free rein to their imaginations. It lets us tap into the variety and creativity which exists in services and supports for children and adults with profound and multiple learning disabilities, without having to relate to a particular theme. We still think themes are important so the other two editions each year will continue to have a particular focus. But for this one – anything goes! It's a bit of an experiment, so we're looking for your support, suggestions and opinions. We also want your ideas for future themes.

My perspectives have certainly changed a lot since I first started working with children with severe and profound learning disabilities way back when. Then, it was shortly after the 1971 Education Act, a time of promise and excitement as the children took their rightful place in school rather than in junior training centres – in England and Wales at least, though not at that point in Scotland or Northern Ireland. Now, we've made great strides with more inclusive schools for children and families, hospital closures, community based services – and many other initiatives. Like all good pioneers we know there's still a lot of land to till, but we recognise our achievements – as evidenced by the wealth of ideas appearing regularly in PMLD Link.

I've had the good fortune to work as teacher, trainer, writer and, at times, jill-of-all-trades, both in the UK and overseas. I have a particular interest in crossing boundaries - social, professional, ethnic and global. Which is one of the reasons I feel drawn to PMLD Link with its breadth of outlook and diversity of approaches. We learn by borrowing ideas from one another, adapting them and making them our own. Turning things on their head. Taking the lead from people with PMLD and their families. Having, as one notable disability activist said, "professionals on tap, rather than on top". Too often, I feel, we get trapped by our own parameters, forgetting to look outside to see what other people are doing.

So, what's going on in your, living room, classroom, school, centre, college or community that we could learn from? Small changes can improve people's lives – how have you changed things for the people with profound and multiple learning disabilities you live and/or work with? Let's have your news and views, your questions and answers, your ideas and experiences. For our next edition, let's go for the wide range of perspectives that makes PMLD Link the important, practice based journal we know it to be.

Thank you

Alice Bradley

Alice Bradley (Guest Editor, Winter Edition on 'Changing Perspectives')

Freelance training and development worker

Welcome to a Parallel Universe

By Jackie Griffiths
Parent

We felt as if a bomb had exploded in our lives. Our beautiful baby girl would be severely, physically disabled all her life, and her respiratory system seriously compromised. The diagnosis of Spinal Muscular Atrophy type 2 was devastating. The family collapsed, unable to function at any level.

We feel that we have joined a parallel universe, another dimension that exists alongside the world BD (before diagnosis). In this new existence we can see out, but very few can see in. On entry to this zone we were gripped by fear and despair, unable to make sense of our new situation. We believed that we were the only inhabitants of this terrifying land and yearned to return home. Gradually, we learnt that there is no return, we are locked in this dimension forever.

Naively, we trusted the Masters of this Universe would provide for our needs. Slowly we came to realise that this is not the case. We learnt that there is not a fair system of operation in this reality, that a genuine need will not necessarily be met. The inability to secure the appropriate care for our child led to anger, frustration and disbelief.

We realised that we were unable to help ourselves because we did not know how to communicate our needs. There is a specialised language that is used in this land that we did not understand, and we were given information about Tilly's condition that we did not want to hear. We were afraid to face the reality of the disease. We became aware that we would have to learn the language and become experts on Spinal Muscular Atrophy in order to achieve results. The process of looking into Tilly's future, in the light of the diagnosis, was torture

The strain upon family life when you enter this dimension is immense. Each member needs so much individual help that they are unable to assist each other. The heartache deepens as relationships disintegrate and children are left bewildered, wondering what has happened to their happy home. There is a crisis of confidence and with so much attention given to Tilly, her big sister feels abandoned and overlooked.

We were staggered to discover the prohibitive cost of living in this dimension. We could never have hoped to bear the financial burden of providing the equipment and alterations to our home needed for Tilly to reach her full potential.

Whilst stumbling through this horrifying landscape we could see the other world delighting in their children, unaware of the simple joys that they take for granted. The pain was intolerable as we struggled to accept the loss of these innocent pleasures for our little girl.

We were told of special clubs in this land where we would be made very welcome, but we didn't want to join. We couldn't accept that we needed these places.

Then one day something wonderful happened. We realised that we were not alone.
There are many families with similar experiences, and we have met them and shared our feelings. These new friendships have healing powers and have allowed us to gain strength to deal with our new situation. We have learnt to laugh again.

We discovered that this dimension is filled with incredibly special people who really want to help. Our family, friends and local community have overwhelmed us with their unending support and love. They are able to reach out from their world and carry us through our difficulties.

Now that the shock of diagnosis has diminished we are able to access a wonderful range of support organisations that this parallel world can offer. We can truly celebrate the joy of our family again, enriched by both our beautiful little girls. We love every day with them and look forward to a fun-filled, exciting future. We are now empowered to accept the challenges and take them on with energy and determination. Tilly and Candice are glorious little girls. They love dancing and sailing and playing together. The Caudwell Charity gave Tilly a fantastic powered wheelchair which has literally opened up the door to Tilly's childhood, giving her to ability to join in.

Tilly has experienced a wonderful blend of education starting with Horton Lodge 'School for Parents' and The Peter Pan Nursery for Children with Special Needs. It was here that we learnt to be comfortable within our new environment. We learnt how to set new objectives and measure success in a different way. A huge challenge was overcome when Tilly attended the local mainstream nursery at three years, with full-time, funded support. This early experience prepared Tilly perfectly for St Edward's First School where the staff and associated agencies have worked tirelessly to ensure a successful and enriching educational journey.

We now have the strength to guide others who join us in this world, and feel inspired to make changes so that entry to this dimension is not so hostile. We are now active in Parent Support Groups working with professionals to improve the lives of families with children with special needs.

As parents living in this parallel universe we understand that we are vulnerable and our voices can fade as we are have to deal with our children's varying health crises. It is essential that a strong and meaningful line of communication and understanding is maintained between the" World of Special Needs and the "Land Before Diagnosis". We have found that the best way to achieve success is by working in partnership with as many agencies as possible.

Our dream would be that at diagnosis, families would not feel jettisoned to a different dimension, but would feel valued, nurtured and supported within a compassionate and caring society.

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The copy date for all articles, information and news for the Spring issue is the 1st March 2007.

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Articles can be long or short and they are welcomed from carers or professionals alike – we value YOUR experience and views. Please contact us if we can help you in any way. If you have any picture or photos to include we would love to see them (providing we have permissions).

The Early Support Family Pack

By Rob Ashdown
Head Teacher, St Luke's Primary

Early Support is the central government mechanism to improve the quality, consistency and coordination of services for very young disabled children and their families. The programme is funded by the Department for Education and Skills through Sure Start and has been developed in conjunction with the Department of Health and the voluntary sector.

Programme materials are available free of charge to parents and those who work directly with young children and their families, in England. The *Early Support Family Pack* is for families with young children with *additional support needs* associated with disability. Printed copies are available free of charge to parents or carers with a baby or toddler in England – and all the contents can be viewed online on the website (www.earlysupport.org.uk).

It is expected that families would be introduced to the Family Pack by someone who is already working with them. It is thought that families get the best out of it when it is explained by someone they know and trust and when it used over a period of time. The pack is designed to facilitate effective partnership working with parents and carers.

The *Early Support Family Pack* is made up of a number of different types of material. In print form, the materials sit in a bright blue plastic box. On the Early Support website the materials are split them into sections for easier access. It pays to look at the *How to use this pack* first.

The *How to use this pack* introduces parents to the materials and explains how they can make a difference. It is recognised that it may seem that the 'system' has taken control and that other people – the professionals – are the only ones who know how to care for the child with disabilities. To their credit, all of the materials stress this is not true and that parents are the most important and knowledgeable people in relation to their child and they are the people that their child needs most.

The *How to use this pack* explains how the empty templates in the *Family File* can be used to co-ordinate discussion and service delivery better. The other materials comprise:

- A one-page '*Overview'***,** which sets out the contents in the *Early Support Family Pack* and explains how the materials are organised. There is a *History* file which is a folder to keep papers in.
- A '*Background information file'* is made up of a series of booklets which explain to parents how services work and how to get help.
- A '*Family file'* is designed to help co-ordinate any support being provided for families.

The *Family file* is intended to be a family-held record, designed to support better co-ordination of services provided for a child and family and more effective exchange of information between professionals working for different agencies. It consists of a number of templates which can be filled in and used by families, or by families and professionals working together. At the heart of the file is a *Family Service Plan* which encourages all the agencies working with a family to discuss the support that is being provided and to agree priorities.

The *Family file* contains the following sections:

- Introducing ourselves
- List of professionals working with us
- Record of professional visits
- Family Service Plan
- What our child can do now
- Current records
- Local organisations and contacts

The *Family File* is only available in printed format as part of the *Early Support Family pack*. Packs are available free to families and professionals in England – go to the website to see how to order. However, to help you to type onto the family file templates - or to print off extra pages you may need - the various sections of the family file can be downloaded as MS Word documents.

The *Early Support Family file* is designed to be used alongside the National Child Health Record Books (the red or yellow book). It adds value to what these materials provide for families where more support is required and/or where co-ordination of multiple contacts is an issue.

The red/yellow book is the key document for health visitors working with families in the first 18 months of a child's life. Health visitors using the Early Support materials for the first time should be aware that families with disabled children asked for something additional to the red/yellow book in A4 format, so they could write on it easily. They also asked for a pocket on the front of the *Early Support Family file* designed specifically to hold their National Health Record Book - the idea being to make it easier for them to keep everything together in one place and to see these materials as linked and responsive to their need for documentation to extend beyond 18 months.

The *Background Information File* is made up of a series of booklets which help families to find out about the services and benefits they need and cut through the jargon that professionals sometimes use. The booklets are available as downloadable PDFs. Some of the files are quite large and may take some time to download (the largest, *Education*, is 2.5MB). They cover the following topics:

- Introduction
- People you may meet
- Childcare
- Financial help
- Education
- Heath Services
- Social services
- Statutory assessment –education
- Glossary
- Useful contacts and organizations

In addition to the material contained in the *Early Support Family Pack*, a number of information booklets have been developed for parents which describe particular conditions or disabilities. They pass on information and suggest ways forward. Readers are also signposted to other useful sources of information and support – publications, organisations, helplines, support groups and useful websites. The *Early Support* website states that each booklet was developed in consultation with families who have 'been there before' and the content reflects what they said it is useful to know in the first couple of years of a child's life.

The booklets are available in downloadable PDF format. Again, some of the files are quite large and may take some time to download:

- Visual impairment
- Multi-sensory impairment
- Cerebral palsy
- Deafness
- Autistic spectrum disorders
- Learning disabilities
- When your child has no diagnosis
- If your child has a rare condition
- Down Syndrome
- Speech and language difficulties

Although no one booklet relates to children with PMLD, clearly several have much relevance, especially the first four in the series. They are produced in A4 format and tend to have the same organizing framework: coming to terms with a diagnosis, what the diagnosis means, getting exact information about your child's diagnosis, getting help, approaches to early intervention , medical interventions, helping your child at home, statutory support for children and their families, books and further sources of information, and useful organisations. The booklets are very useful and remarkably free of medical or educational jargon. However, they do need to be introduced to the family by someone who fully understands these conditions and their implications for the family and the child's development.

Overall, the materials and the information on the website are incredibly useful and they are free. If you have not yet seen them, make a point of viewing them as soon as possible. Of course, much depends upon how sensitively families are introduced to the materials by professionals who work with them. There is nothing to be gained by giving the *Family Support Pack* to a family and leaving them to wade through it by themselves. Also, there is a whole package of training which is considered necessary for professionals to pursue if they are going to support families.

The materials have only been available for over a year. Nevertheless, there are already concerns about whether local authorities are getting their act together to make the materials as widely available as possible. Also, what will happen to these family records when the children actually enter school? It is far from clear to what extent local authorities and schools will bend the whole cumbersome bureaucratic practice surrounding formal assessment, annual reviews of statements and reviews of individual education plans to support families in the continued development of their family-held records and their role as the enduring educators and equal partners in their child's education at school. In all probability many local authorities and schools might not have given the issue much thought at all yet.

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The early support materials are available on the programme dedicated website:
WWW.earlysupport.org.uk

Portage

By
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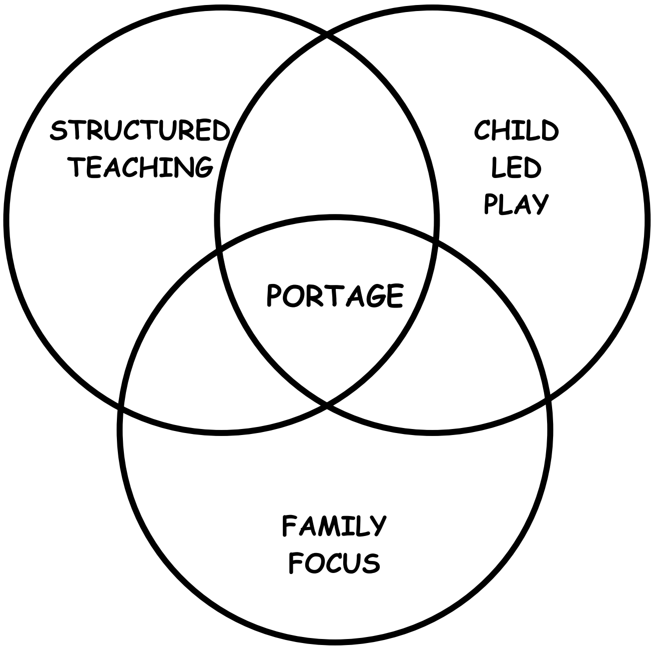
This year Portage in the UK is celebrating thirty years of partnership with young children who have additional needs and their families. Over these years Portage has developed and been extended to work with children with a very wide range of needs, including those who have profound and multiple learning difficulties.

Portage is a home visiting educational service, which aims to help families and children play and learn together, using what the child enjoys and can already do as the starting point for any activities. It also works to help minimise the barriers confronting families, to help ensure that they are included in their community and to develop inclusive services.

The Portage model has several key elements but is based on the developing partnership with families. There are regular, usually weekly, home visits by the same person and an individualised curriculum is designed for each child. Everyone who knows the child well is involved with these plans, including family members and any professional who might also be helping the family. The plans aim to reflect family priorities and can be very varied including skills in all areas of development.

No two home visits are ever the same although there are three elements, which are always present. These can be illustrated as follows:



Detailed observations of how a child plays are used to help make an assessment of what is enjoyable and achieved without any help. These observations help to plan what to teach next and the best way to do this. For children who have a combination of very complicated needs and who therefore often learn very slowly, the Child Led Play element of the Portage model looks at the smallest changes and responses, which are then used to plan a sensory curriculum and activities.

How any new skill or sensory experience is introduced and taught is very carefully planned so that everyone knows exactly what is needed; what to say; where to do the activity and so on. What is important to the family at the time of the home visit will affect what happens and sometimes much of the visit will be spent in talking about a particular issue, such as the results of a visit to the hospital, arrangements to attend a new group, or the birth of a new baby.

Portage uses a small step approach to learning. New skills are taught in a very structured way but so that the activities fit in with the usual daily routine. Families often find this added structure helpful in the busy lives they lead. The structure and support, which is part of the Portage model, can be especially helpful to parents who have children with a combination of very complicated needs.

All aspects of Portage are underpinned and overarched by a set of principles, which are shown on the next page. The Portage approach, with its emphasis on partnership and bringing together the knowledge and expertise of all those involved with the child, fits well with the implementation of the 'Team Around the Child' model.

The National Portage Association exists to bring together all those involved in Portage in the UK and to oversee the quality of training and service delivery. Further information about Portage in the UK can be found on the NPA website www.portage.org.uk

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Integrated Programmes and the Primary Interventionist in Early Childhood Intervention

By Peter Limbrick
Interconnections

Peter Limbrick is an ex-teacher of children with disabilities and special needs and an ex-sibling, as his younger brother with cerebral palsy died a few years ago. Since 1990 Peter has been campaigning in various ways for effective support for these children and their families. This has included writing and consultancy work under the name of Interconnections, establishing the charity One Hundred Hours, and then chairing the Handsel Trust which succeeded it.

Summary
There is significant benefit to babies and pre-school children with PMLD, to their families and to their practitioners when all interventions for development and learning are pulled together into an integrated or whole-child approach. Integrated programmes will cater for children who are not yet ready to compartmentalise activity. Provision of a Primary Interventionist will protect the child from exposure to more practitioners than they can accommodate. Both models offer practitioners opportunities to work together in a trans-disciplinary approach and create flexibility in how they use their time.

Who needs an integrated programme?

I would suggest that all babies and pre-school children with PMLD will benefit from some integration of their development and learning programmes, whether provided by teachers, therapists or others. Though practitioners might specialise in the separate disciplines of perception, movement, communication, understanding, etc., it is a mistake to assume babies and young children can compartmentalise their activity in the same way. Infants with PMLD are likely to bring their whole being into each situation they encounter, each activity requiring some integration of posture, movement, language, dexterity, perception, emotions and social skills. It is the whole child we must have in mind when we plan interventions – just as parents of young children do naturally.

What would an integrated programme look like?

It is probably best to think in terms of providing activity for the child which is natural, meaningful and enjoyable rather then puzzling out how to join various discipline-specific activities and goals together into some composite multi-disciplinary programme. This approach follows the principle of starting where the child is, rather than starting from where we are as separate practitioners. The integrated education/therapy activities then will be part of the daily routine (mealtime, bath-time, bedtime, dressing, moving around the house, socialising, playing, etc.) The task of each practitioner is to incorporate their required work into these activities so that it fits naturally and becomes part of a routine which is always developing. Practitioners' goals might have to be prioritised to keep the amount of new work within the child's capacities and care must be taken to ensure that each activity includes elements in which the child is already competent, elements he still needs to practice and elements which require new learning. The aim is to provide new opportunities for development and learning at the child's pace and which maintain or enhance his enjoyment and involvement.

Who needs a Primary Interventionist (PI)?

A Primary Interventionist is a practitioner who, by agreement, does more work with the child and parent than do the other practitioners who are also involved with the child's development and learning. In early childhood intervention the child, parent and PI will work together in a threesome. The PI has validity for babies and children who are not yet able to form multiple relationships or accommodate a number of people handling and working with them. In my experience, this group of children would include babies (whether premature or not), infants with significant sensory impairment and infants who are generally ill at ease, or fearful, of the world around them and the people in it. Readers will be able to add to this list. The PI will be the first practitioner to carry on and extend the work begun by the parent, and is the main person providing the baby or young child, in partnership with the parent, with development and learning opportunities as prescribed by the other key practitioners involved with the child and family. For some families the first task of the PI will be to help the parent and baby relate to each other.

Obviously, it is expected that for most children with PMLD the need for a PI will be a phase that will lead, sooner or later, to acceptance of a widening group of people. As the child gets older a widening group is inevitable, but for some infants, the PI represents the best response services can make to the child's needs in early intervention.

Who can be a Primary Interventionist?

Any of the child's practitioners can, by agreement, become the PI for a specified period. If one of the therapists or teachers is chosen, then the other therapists and teachers will benefit by gaining time to spend with other children. This can help compensate for the additional time spent in coming to agreement about integrated programmes and PI. If the person chosen as PI is a practitioner who can see the child on a daily or weekly basis (for example a nursery nurse or a Portage worker) then it is probable that the child will have more frequent exposure to each practitioner's work than would otherwise be possible. A practitioner who can see the child only once every few weeks will have the reassurance that the child is benefiting from her intervention on a regular basis – even if the intervention is indirect most of the time.

What responsibilities do practitioners have when working with integrated programmes and Primary Interventionists?

The primary concern is to ensure that these models of working result in the child having increased exposure to the development and learning opportunities prescribed by the key practitioners, and that each practitioners feels her skills, knowledge and experience are impacting on the child and family more effectively than in the traditional model of separate interventions and multiple programmes. Babies and pre-school children with PMLD have a right to support from the full team of highly trained and experienced therapists, specialist teachers and play specialists. Integrated goals and PI are a means to bring all of this expertise together into a whole approach.

Integrated programmes and Primary Interventionist approaches both invite practitioners to work within a consultant model, exchanging skills, knowledge and understanding with colleagues. Boundaries are softened and there is willingness for sharing both general and child-specific information between disciplines. Each practitioner gradually widens and deepens her knowledge base and range of skills, and by doing so enhances her own specialism and practice. To maintain standards at the highest possible level, each practitioner who provides part of her programme to a child through a PI can apply a code of practice. My suggestion for this is:

1. Ensure the PI is competent to take on the work.
2. Ensure the PI has the necessary time and resources.
3. Give necessary instruction and training with written or video notes if required.
4. Provide ongoing support as necessary.
5. Monitor PI's performance, give helpful feedback and ask for feedback from PI.

Training

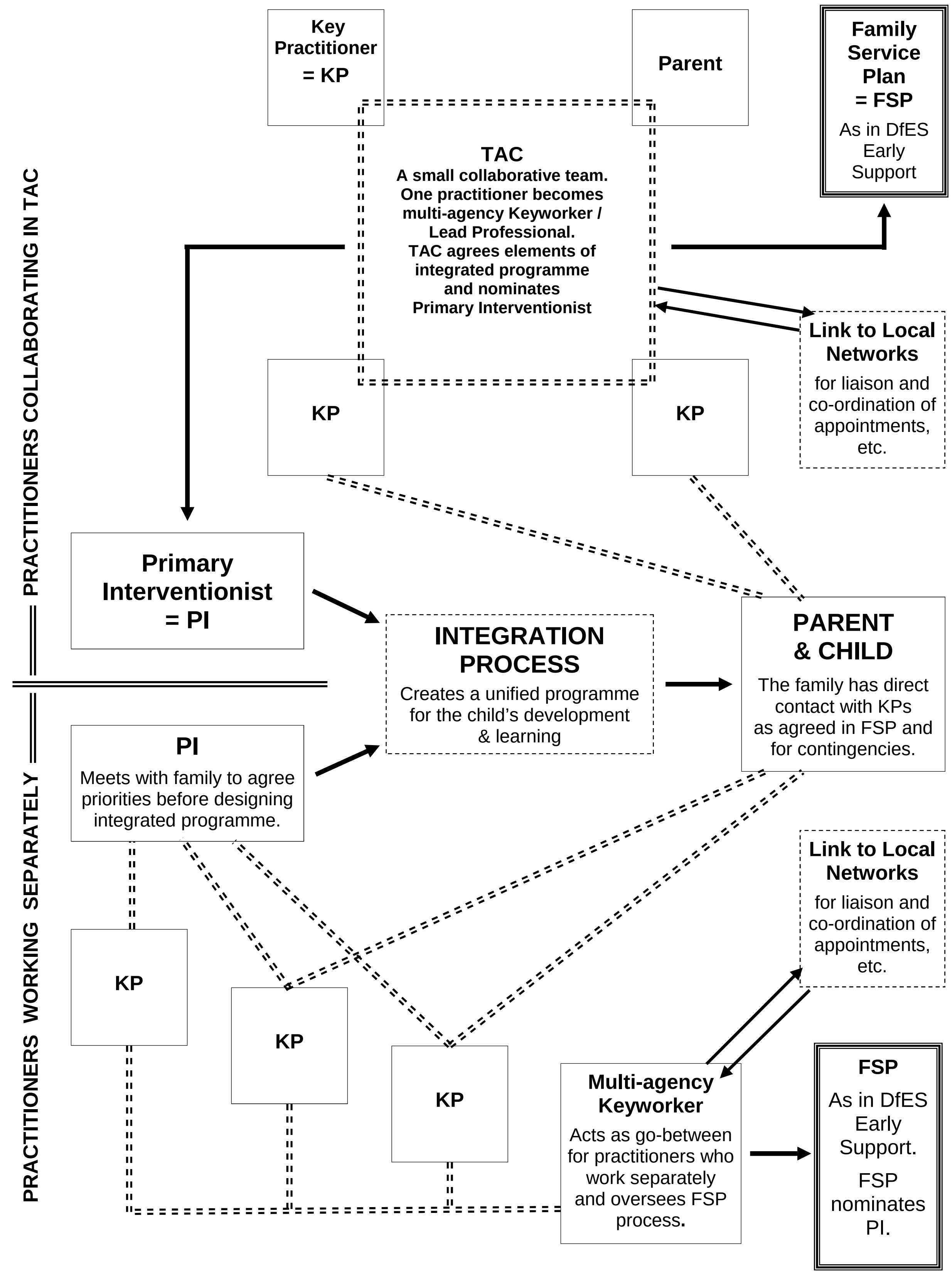
Any council department, health trust, or integrated health/education/care service that expects its practitioners to adopt these practices must provide for their training and support needs and for the smooth transition from traditional separate working to new collaborative activity. The foundation of this training must be a multi-agency effort to facilitate multi-disciplinary practitioners getting to know each other and learning to respect and trust each other. In this in-service training, practitioners can learn *about* each other at the same time as they are learning *with* each other. Until these inter-practitioner relationships are established all plans for close collaboration will come to nothing.

4. The One Hundred Hours (OHH) experience

During the 1990s One Hundred Hours (OHH) provided keyworker-based support to families of neurologically-impaired babies and young children. This was a voluntary organisation in Yorkshire, established to develop and validate the Keyworker-model of child and family support. Each Keyworker was a trained and experienced professional (nurse, social worker, teacher, health visitor, etc.) who was then employed by OHH with the single role of Keyworking for one or more families. Having at that time no useful guidance about what Keyworkers should do, OHH allowed the role to develop during the decade in a tri-partite partnership between families, Keyworkers and OHH management. A full account of OHH can be found in *The Keyworker – a practical guide*, but I will focus here only on how the Keyworker could, if the family wished, generate integrated programmes and become the Primary Interventionist. I shall refer to the Diagram which appears at the end if this article. Though I have used 'Primary Interventionist' and 'Team Around the Child (TAC)', neither of these expressions was used at that time within OHH.

The Diagram shows that the Keyworker had two options when the family were looking for some integration of interventions. In the first and far less satisfactory option, the Keyworker would assume the role of go-between amongst the child's key practitioners (usually therapists and pre-school specialist teachers). The Keyworker's task was to invite them to provide some part of their intervention as consultants. The Keyworker would

TWO APPROACHES TO PROGRAMME INTEGRATION IN THE ONE HUNDRED HOURS MODEL



= = = = = = = = = = = = = = = Denotes people working together, as far as possible, in relationships based in mutual honesty, trust and respect.

then integrate these separate activities and goals into an integrated programme. This approach was used when key practitioners were working separately from each other in the traditional approach. If practitioners did not choose to adopt a consultant role with the Keyworker, then the Keyworker could integrate whatever home programmes practitioners had given to the parent.

The much more successful option was for the Keyworker to invite key practitioners to work together in a TAC, or, as happened in one instance, to join an existing TAC-type meeting. The clear benefit of this option is that key practitioners, parent and Keyworker are in regular and close collaboration and can modify and adapt their interventions as they learn at first hand what the other people are thinking and doing. The first option requires the Keyworker to carry the responsibility to integrate interventions, while in the second option, the key practitioners assume a collective responsibility to integrate their interventions. In my view, this is common sense and obvious good practice for children and families who require multiple and complex interventions.

Two further points are worth making. The first is that each practitioner who works as a consultant must come to a decision with each family about what direct contact she will continue to have for review, assessment and any specialised interventions. Secondly, therapists might be involved in some form of treatment as distinct from helping the child's development and learning (e.g. chest drainage). This article does not concern itself with such treatment.

In conclusion

There is an increasing population in the UK of children who require on-going multiple interventions. In my experience there have always been some families whose practitioners have worked together under their own initiative to provide a coherent and integrated approach. There are many other families whose children have had reduced learning opportunities because of confusion, contradictions and inconsistencies. My appeal would be for new multi-agency systems which provide all young children with PMLD with integrated support by facilitating practitioners in a collective and collaborative response to the child's needs. A significant move in this direction would be for service providers and practitioners to adopt a code of practice for each practitioner to apply when first meeting a family with a baby or pre-school child with PMLD. I offer the following suggestions as a starting point for developing a code of practice:

1. Ask the parent which other services and practitioners are already involved.
2. Check that the family and the child are ready for another practitioner to be directly involved. If not, decide if the new work can be offered on a consultant basis.
3. Find out what approaches, programmes, goals, etc. are already in place.
4. Ensure that any new work offered fits well with these existing interventions.
5. If there is already a TAC operating, make contact with it, and if there is not, suggest establishing one.

Neither integration of programmes nor provision of a Primary Provider require busy practitioners to add to their workload. Both developments can be part of a radical reconfiguration of service provision for children and families who require multiple interventions. To succeed, this must be an initiative at strategic level, with full involvement of families and practitioners, in which fresh decisions are agreed about how practitioners' time and skills are best employed. Peter is happy to enter discussion with readers by e-mail.

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Health Visitor
Best Practice Guidelines For Disabled Children and those with Complex Health Needs.

By
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Health Visitor

Staffordshire Moorlands Primary Care Trust (PCT) was invited to consultation meetings with parents of children with a disability/ complex health needs in 2004-05. The consultations were deemed necessary due to concerns raised by parents regarding inconsistent patterns of health service provision for children with special needs. This was particularly pertaining to Health Visiting and School Nursing. It was identified that lack of continuity and barriers to effective health service delivery were apparent for this group of children/families.

Perceived barriers to effectual service delivery included:

- Inconsistent patterns and continuity of health service provision for children with disability/ complex health need and their families
- Lack of recognition and formal review
- Lack of co-ordination between multiple service providers
- Exclusion from some mainstream and community services and facilities

This is consistent with findings in Standard 8 of the National Service Framework for Children (DoH, 2004) and research undertaken by Sloper (1999)

It was accepted that parents valued the support from Health Visiting and School Nursing, but providing a seamless service is not without its logistical difficulties. According to Williams et al (2005) difficulties in providing a seamless child surveillance service is partly due to:

- Health Visitor Shortages
- Staff Sickness
- Vacant Caseloads
- Difficulties in Recruitment/Retention of Health Visitors

Due to these logistical problems children with a disability/ complex health needs are at risk of not being recognized, as currently they are not followed up in any formal identifiable way. Thus opportunities to provide essential support and service delivery could potentially be missed.

In response, with full management support, a multi agency working party was formed with health visitor representation from all PCTs in North Staffordshire, allied health services, social services, voluntary services and parents. The remit of the working party was to produce best practice guidelines for additional health visitor contact and a checklist providing guidance for practitioners when supporting families. This was deemed necessary in order to offer the appropriate level of support. This guidance is in addition to the Core Child Health Promotion Schedule for North Staffordshire (Williams et al 2005) (Appendix 1)

Health visiting is a universal service with a remit to target service delivery flexibly in response to recognised and identified needs.

According to Every Child Matters (DoH, 2003a), all children have the right to be given the best opportunity to reach their full potential in life. Where children have a disability or complex health needs, it is important that these are identified as early as possible, and that identification leads directly to effective ongoing intervention and support by health and allied services.

It is proposed in the National Service Framework for Children (DoH, 2004) that assessment for disabled children and those with complex health needs should not be regarded as a single event but rather as a continuing process. It is advocated that early assessment of need, where possible, in terms of medical, social, and educational needs, is essential to secure and define appropriate service provision. Use of the Common Assessment Framework (DfES, 2004), a nationally standardised approach to aid practitioners in identifying and meeting needs will facilitate this. The integrated support offered by appropriate assessment could best be coordinated by a practitioner in a lead role, e.g. the Health Visitor acting as the Lead Professional (DfES, 2004).

Central to the purpose of the Best Practice guidelines is ongoing assessment to promote:

- Effective identification/sensitive assessment of disability/ complex health needs
- Ongoing emotional support for parents as appropriate
- Improved co-ordination of multi-agency support for families
- Improved information and access to services for families
- Improved professional knowledge and skills
- Service review, appropriate training and professional development
- Partnership across agencies and geographical boundaries

Liberating the public health talents of Community Practitioners and Health Visitors (DoH & CPHVA, 2003) identifies the principle of ensuring services are accessible to those whose needs are greatest. Health Visitors are in a key position to recognise, refer and support families of young children with a disability/ complex health need (Portway & Johnson 2002).

Focal issues of emotional support, poverty, poor housing, and unequal access to education, healthcare, leisure activities, respite and transport would become part of an ongoing holistic team assessment. This will help develop a service that is responsive to, and inclusive of, individual need.

Children with a disability/ complex health needs are classed as a vulnerable group and each Primary Care Trust must demonstrate its commitment to reducing inequalities in health as set out by Government targets. By focusing on areas that can make a difference, the life chances of those in need will be enhanced.

Definition of Disabled children and those with Complex Health Needs

The National Service Framework for Children, Standard 8 relates to:

"children and young people who are disabled and/ or those with complex health needs, including children and young people with learning disabilities, autistic spectrum disorders, sensory impairments, physical impairments and emotional/ behavioural disorders. Many disabled children have no need for ongoing health interventions; others require ongoing treatment and/or nursing care and help with the everyday activities. Some disabled children will also be children in special circumstances."

Taking this into account the following definition is used for the purpose of these Guidelines for Best Practice.

A child under 5 years of age shall be considered as having a disability/ complex health need if he/she:

(i) is experiencing significant developmental impairment or delays, in one or more areas of cognitive development, sensory or physical development, communication development, social behavioural or emotional development;

and/or

(ii) has a condition which has a high probability of resulting in developmental delay. (DoH 2003)

and/or

(iii) requires two or more health services other than health visiting, or where there is parental/ professional concern.

Best Practice Guidelines for Children with Special Needs.

Holistic assessment of Children with a disability/ complex health needs is on going as it for all children. However additional points of contact are recommended in addition to the Core Child Health Promotion Schedule (Appendix 2) and will consist of :

Home Visit (or telephone contact depending on parental preference) at point of identification of disability/ complex health needs and thereafter as appropriate at:

- 3mths
- 6mths
- 18mths
- 3yrs
- 4yrs

Benchmarks for holistic assessment should include:

- Enquiries about child/family health
- Review of previous development history/ referrals
- Enquiries about concerns over development, behaviour, hearing, vision, speech

- Health promotion appropriate to age and situation
- Reassessment of family needs as appropriate regarding:
  physical health/ emotional health/ practical needs/ financial/ respite/ socio-economic support
- Follow up of parental concerns
- Direct referral/ liaison of identified concerns if appropriate
- Documentation completed as per PCT guidelines and inclusion on Parent Held Record

In addition to the above, for children identified with a disability or complex health need, it is recommended that the Disability/ Complex Health Needs Checklist is used as guidance for service review/support (Appendix 2)

Conclusion

The needs of the child and family will change over time as a result of the child's development, family factors and as an outcome of the support provided. The ongoing contact/assessment process must be flexible and responsive to changing needs. Incorporating the Best Practice guidelines and checklist will go some way to achieving this.

Children with a disability/ complex health needs are first and foremost children, with all the rights and aspirations of any young children. Ensuring their rights are met requires service provision in line with the United Nations Convention on the Rights of the Child, the Human Rights Act (1998) and the Disability Discrimination Act (1995).

Health Visitors bring their prevalent knowledge of holistic assessment of need to any additional responsibility. In Every Child Matters (DoH 2003a) the importance of early intervention and effective protection of children is emphasised, arguing that the key is to ensure that children receive services at the first onset of problems, so that no children slip through the net.

Early identification and early intervention are key themes in the Framework for the Assessment of Children in Need and their Families (DoH, 2000) and the Special Educational Needs Code of Practice (DfES, 2001). They are central to a number of Government initiatives including Quality Protects, Sure Start and the National Service Framework for Children, Standard 8 (DoH, 2004) and should lie at the heart of care provided by all professionals. (DoH, 2003b)

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Appendix 1

Core Child Health Promotion Programme - North Staffordshire
(Williams et al 2005)

Item	Age	Contact	Practitioner
1	Antenatal	Client interview	Midwife/Obstetric team/GP/HV
2	0-1 wk	Examination of the Newborn	Appropriately trained health professional.
3	First 48 hrs	Universal Neonatal Hearing Screening.	Trained Audiometric Screeners
4	6-28 days	Neonatal Blood Screening	Midwife
5	5-10 days	Midwife to HV transfer of documentation.	Midwife
6	10-14 days	Primary Visit	Health Visitor
7	10-21 days	Initial Assessment	Health Visitor
8	6-8 wks	Examination	GP or Health Visitor
9	8 wks	Immunisations	Health Visiting Service
10	12 wks	Immunisations	Health Visiting Service
11	16 wks	Immunisations	Health Visiting Service
12	12 mths	Immunisations/Assessment	Health Visiting Service
13	2yrs – 2yrs 3mths	Assessment	Health Visiting Service
14	3 ½ yrs	Assessment	Health Visiting Service
15	4 ½ yrs	Transfer of documentation to named school nurse	Health Visiting Service
16	4-5 yrs	Orthoptic Check Commencement of school health programme/ assessment	Orthoptist School Nursing Service
17	11-12 yrs	Assessment	School Nursing Service
18	12-13 yrs	Immunisations	School Nursing Service
19	13-14 yrs	Immunisations	School Nursing Service

Appendix 2
Best Practice Guidelines for contact for Children with a Disability/ Complex Health Needs

These guidelines have been produced by a multi agency working party of health visitors, allied health services, social services, voluntary services and parents. The highlighted text is the proposed additional contact recommended for children with a disability/ complex health needs.

Item	Age	Contact	Practitioner
1	Antenatal	Client interview	Midwife/Obstetric Team/GP/HV
2	1 wk	Examination of the Newborn	Appropriately trained health professional
3	First 48 hrs	Universal Neonatal Hearing Screening	Trained Audiometric Screeners
4	6-28 days	Neonatal Blood Screening	Midwife
5	5-10 days	Midwife to H.V transfer of documentation	Midwife to H.V
6	10-14 days	Primary Visit	Health Visitor
7	10-21 days	Initial Assessment	Health Visitor
8	6-8 wk	Examination	GP/Health Visitor
9	8wks	Immunisations	Health Visitor
10	**12 wks**	**Additional Contact** Immunisations	**Health Visitor**
11	16 wks	Immunisations	Health Visitor
12	**6mth**	**Additional Contact**	**Health Visitor**
13	12 mths	Immunisations/Assessment	Health Visitor
14	**18mths**	**Additional Contact**	**Health Visitor**
15	2yrs -2yrs 3mths	Assessment	Health Visitor
16	**3yrs**	**Additional Contact**	**Health Visitor**
17	3 ½ yrs	Immunisations/Assessment	Health Visitor
18	**4yrs**	**Additional Contact**	**Health Visitor**
19	4 ½ yrs	Transfer of Documentation to School Nurse	Health Visitor

Changing Places - Changing Lives

By Beverley Dawkins
Mencap

Sometimes you just need to change one thing to open up a world of possibility. The public places that most of us take for granted – stations, hospitals, shops, cinemas and museums – are only accessible to us because they offer the most basic facilities. Like toilets….

Standard accessible toilets do not meet the needs of all people with a disability – or their carers. Many people with profound and multiple learning disabilities need support to use the toilet, or require the use of a height adjustable changing bench where a carer can safely change their continence pad. They also need a hoisting system so they can be helped to transfer safely from their wheelchair to the toilet or bench.

Standard accessible toilets do not provide changing benches or hoists, and most are too small to accommodate more than one person. This means that family members are forced to risk their health and safety – and that of their loved one – by changing them on a toilet floor. This is dangerous, unhygienic and undignified. Paid carers are not even allowed to attempt this, meaning that many people with profound and multiple learning disabilities are unable to take part in activities enjoyed by others at their day centre, school or college.

The **Changing Places Consortium** will launch a campaign in July on behalf of the thousands of people who cannot use standard accessible toilets. They need **Changing Places loos**. These loos provide:

The right equipment
A height adjustable changing bench
A tracking hoist system, or mobile hoist

Enough space
Adequate space in the changing area for the disabled person and up to two carers
A centrally placed toilet with room either side for the carers
A screen or curtain to allow the disabled person and carer some privacy

A safe and clean environment
Wide tear off paper roll to cover the bench
A large waste bin for disposable pads
A non-slip floor

The Changing Places Consortium want Changing Places loos to be installed in **all big public places,** including city centres, shopping centres, arts venues, hospitals, motorway services stations, leisure complexes, large railway stations and airports. Changing Places loos should be provided **in addition** to standard accessible toilets.

The Changing Places Consortium is a group of organisations working to support the rights of people with a learning disability to access their community. It includes Mencap, *PAMIS,* Nottingham City Council, Dumfries and Galloway Council, the Department of Health Valuing People Support Team, and the Scottish Executive Same as You Team.

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Addressing the impact of Exaggerated Lumbar Lordosis on the quality of life of a young man with severe and complex learning disabilities in a residential school.

By

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Edited from a longer version by Di Foxwell, *Coordinator of Clinical Education and Practice Development, Berkshire Healthcare NHS Trust*

Introduction

This paper describes the impact of exaggerated lumbar lordosis upon the quality of life of a young man, named John (pseudonym), who has severe and complex learning disabilities. The paper will suggest a plan of action to enable the staff who work with him to increase his facility in carrying out routine personal care tasks in the long term. In the course of researching for this paper, conversations took place with key professionals, and observations were carried out. John's mother gave her consent for John to participate in the research project and for this paper to be written. John also gave his consent, insofar as he could understand, for the researchers to work with and observe him.

Exaggerated lumbar lordosis

The normal spine, viewed from the side, is curved, and the lumbar (lower) spine has a lordotic or anterior curve. Exaggerated or excess lumbar lordosis describes a condition in which the lumbar spine curvature has become exaggerated. Lordosis is a common condition, which does not elicit undue medical concern, and there are no reliable prevalence figures available. It can be variously associated with specific syndromes (e.g. achondroplasia, William's syndrome), with particular life stages (e.g. pregnancy) or with lifestyle (e.g. obesity, sports such as dance), as well as congenital abnormality, injury, infection, etc. It is the result of the body's attempt to compensate for postural imbalances, and is often taken to be indicative of hip flexion and poor muscle tone in the muscles of core stability in the torso.

The complications which arise from lordosis can be physiological and neurological. It can result in an increased anterior tilt of the pelvis, and may compromise the person's range of motion and motor function. In young people, it often self-corrects; however, once excessive lordosis has developed, it can become a permanent condition which may result in increased strain on the lower spine. This may become associated with disc prolapse or osteoarthritis later in life (Moore and Agur, 2002; Regan, 2002; Regshauge and Gass, 2004; Thibodeau and Patton, 1992).

Non-invasive treatments can include reducing body weight to the ideal, and physical therapy which enables the person to build strength, flexibility and range of motion. In severe cases, medication, bracing and surgery may be indicated.

Background

John is a young man of 14 years who currently attends a school which offers education and 52-week residential care for young people between the ages of 6 and 19 years with severe and complex learning disabilities. He lives in a bungalow within the school grounds with seven other young people with severe and complex learning disabilities. John's daily care is provided by his Key Worker and the Residential Care Team, an Occupational Therapist (OT), the Speech and Language Therapist (SLT), an Assistant

Psychologist and his Class Teacher and Education Support Workers. John is described in his Statement of Special Educational Needs as having 'severe global delay' and challenging behaviour. The statutory Education Advice associated with this describes him as having severe learning difficulties, with severely delayed speech and language development and 'major behaviour problems'. He also has additional health needs.

Description and implications of John's additional health needs

In 2004, the OT identified a number of postural needs, resulting in reduced body awareness and motor skills. The OT described John's postural imbalances as including an anterior pelvic tilt and a lordosis, which may result in difficulties with posture, body awareness, and gross and fine motor movements, bilateral integration (using both hands co-operatively), and fine motor manipulation (Dutton, 1998).

Postural and motor needs can arise as a result of poorly functioning sensory systems – particularly the vestibular, proprioceptive and tactile systems. Tactile input is mediated through receptors in the skin, which feed back about light touch, deep pressure, temperature, pain, crude touch and discrimination. Proprioceptive information about the position of the body, and how it relates to everything around it, is received from muscles, ligaments, tendons and joints. The tactile and proprioceptive systems together make up the somatosensory system. There are two main nerve pathways regulating the somatosensory system – the anteriolateral system (ALS) and the dorsal column, medial lemniscus system (DMLS). The ALS mediates crude touch, and is related to the fight or flight response. The DMLS conveys discriminatory information (i.e. about temperature, texture, vibration, pressure and where the body has been touched). This system facilitates fine motor movement (e.g. writing) and posture (e.g. sitting, looking around). In the typically functioning somatosensory system, the DMLS 'gate-keeps' the ALS, which overrides the DMLS only in fight–flight situations. For people who have a neural dysfunction in which the dorsal column pathway is not working effectively, the ALS may predominate. This can generate a state of heightened anxiety. As a person's anxiety levels rise, their skills of sensory integration decline. They lose the sense of where their body is in space, and need greater proprioceptive input before they feel or perceive sensation (cf. Juliano and McLaughlin, 1999.)

John's difficulties with body awareness and tactile discrimination suggest that he has sensory integration needs and that his tactile system does not function typically. His Residential Care Team say that he often appears unaware that his body has moved (e.g. when his head becomes out of alignment with a cup when drinking) or of how to move his body in order to achieve a desired outcome (e.g. putting legs into trouser openings). The OT has noted that he appears unaware when he has injured himself, and does not protect the injured body part from further injury (e.g. knocks). When agitated, he seeks extreme proprioceptive or deep pressure input, e.g. biting his hand, banging his head against hard surfaces. His lack of awareness of and response to drooling and incontinence also suggest impaired sensory feedback.

All these issues have significant implications for John's immediate quality of life – his ability to carry out daily living activities effectively, his safety (e.g. perception of temperature), personal hygiene (e.g. continence), and general health (e.g. effects of impaired posture). Additionally, there are implications for his long-term quality of life, because as he becomes older and less active, his body may become unfit and unable to accommodate dysfunction, which could lead to his becoming a wheelchair user. It is important to ameliorate any consequences through intensive work to reduce postural imbalances.

John's understanding of his health needs and the purpose and consequences of occupational therapy are limited; however, he is able to indicate preference verbally and to make choices supported by the Picture Exchange Communication System (PECS; Frost and Bondy, 1994, 1998). Although, as with many young people with severe and complex learning disabilities, John expresses strong negative feelings about situations through challenging behaviour.

John's enjoyment of the OT/SLTs' sessions is apparent through his willingness to take part in the activities, his relaxed demeanour and his enjoyment in developing his own 'games' within the structure of the sessions, which allows him a certain level of control (permitted by the OT and SLT) within the activities.

Planning the intervention

A plan of action was drawn up in consultation with the OT to introduce an intervention to support the OT's work on reducing the effects of his lordosis. This would enable the Care Support Workers to implement occupational therapy strategies within the context of John's daily living in a way, which would ultimately have a positive impact upon his quality of life.

Firstly the skills to be worked on were identified during OT/SLTs' sessions through interview and observation. These were identified as:

1. To engage his muscles of core stability
2. To work towards correcting his postural imbalance.

The OT used the strategies described overleaf drawing on the work of Dutton (1998), Sheridan (1997), Ayres (1979) and Bobath (1990).

Identification of skills within the residential care setting

The Residential Care Team were working on ways to build up positive interaction with John and also on his skills of daily living through targets set as part of his Individual Education and Care Plan (IECP) (Carpenter et al, 2001) Staff found it difficult to support targets such as dressing since his disabilities meant that often the lowest target levels were above his current physical capacity. This was demoralising for both John and staff.

The researchers judged that specific quality of life aspects could be improved if:

(a) IECP targets were attainable for him and could be met through activities he enjoyed leading to improved self-esteem, and therefore increased opportunities for positive interaction.

(b) Occupational therapy targets could be incorporated into routine activities to increase repetition of occupational therapy exercises leading to maximised improvements in relation to occupational therapy aims and John's long-term health prospects.

(c) His sensory needs could be met within enjoyable activities leading to a sense of fulfilment for John and positive interactions with staff leading to increased self-esteem.

John's severe learning disability meant that he was not able to be involved directly in the planning of the occupational therapy interventions. However, it was important for his self-esteem that activities identified were fun and engaging for him.

Dressing skills were selected as the focus target. In order to identify areas of difficulty during dressing, an activity analysis of performance components was carried out in association with John's Residential Care Team, and it was related to John's difficulties. From this, it was apparent that John has difficulties in many skill areas that are foundational to dressing:

- His postural imbalance means that he has difficulty in moving his limbs across the vertical midline of his body, therefore managing sleeves, etc., is difficult for him.
- He has difficulties with bilateral integration (specifically, simultaneous use of both hands), therefore finds difficulty in pulling on trousers and tops.
- He has a poorly functioning tactile system, causing difficulties when manipulating clothing.

It was therefore apparent that even basic dressing-specific IECP targets were beyond John's current scope. However, it can be argued that staff would be justified in working towards foundational pre-dressing skills, such as increasing his fine motor facility through engaging his muscles of core

Table 1: John's progression towards the OT's aims during occupational therapy/speech and language therapy sessions (June 2004 – May 2005)

Activity	OT aims and rationales	Progression
Balancing on the gym ball *The OT and SLT devised a game whereby he would bounce on the gym ball – first holding the OT's hands and then, when his balance had improved, independently.* *This game started the session and was repeated between activities to improve John's body awareness.* *John remains seated on the gym ball throughout the session.*	Aim: For John to centre himself maintaining an upright sitting posture on the gym ball; i.e. sit symmetrically with both shoulders level, equal weight on both hips, hips symmetrically abducted, and feet flat John needs to engage and flex his muscles of core stability in order to remain upright, thus strengthening them as he balances. This encourages John to sit with an upright posture, in a position which stabilises his shoulder and pelvic girdles which, in turn, allows him an opportunity to improve his motor skills. This encourages John's body awareness.	1 First session: John was unable to remain upright while being seated on the gym ball as his muscles lacked strength 2 Now he sustains an upright sitting posture on the gym ball with little difficulty. 3 Early sessions: John showed little awareness of how his body was positioned, and needed physical assistance to move his feet. Often his feet would be splayed to the sides in non-load-bearing positions. 4 Early sessions: if he needed to move in order to carry out an activity he found difficulty in identifying where his feet were and where he needed to move them to in order to carry out the activity. 5 Observed session: on being told that his foot was on top of his favourite symbol, he lifted up the right foot, moved his leg and placed it in such a way that he had the postural stability to lean forward and pick up the symbol. 6 Now, He places his feet in a position which offers him stability.
Exercises promoting forward and lateral flexion initially using gravity – reaching and pulling	Aim: To encourage forward flexion using abdominal muscles and strengthen John's muscles of core stability This exercise builds up John's stability.	1 Early sessions: he picked up symbols from the floor (in front) and handed them to the OT 2 Gradually different directions were incorporated, to build up spinal and abdominal musculature 3 Observed session: he reached for symbols directly in front of him at shoulder level, on the floor, to the side, pulled them off the Velcro, and rotated his body to gain eye-contact with the OT and SLT. 4 He picked up symbols with one hand and transferred them to the other before matching them (i.e. spontaneously crossing the body's vertical mid-line), which he had could not do initially.
Weight-bearing through arms to move around on a wedge on a smooth surface (used in the course of SLT activities)	Aims: To work in prone extension (John had good supine flexion) To improve weight-bearing through John's arms and stability in his shoulder girdle John received deep proprioceptive input and increased his body awareness	5 Over the course of sessions, he became more aware of where his body was in relation to the environment and what he needed to do to move himself in relation to his posture. 6 I did not observe this activity.
Identifying objects through touch (stereognosis) while balancing on the gym ball to maintain posture	Aim: To assess progress towards increasing his ability to do fine motor tasks	7 If this exercise is carried out before the postural exercises, he has a very low identification rate of objects. 8 If this exercise is done afterwards, he achieves an approximate identification rate of 75%. However, this remains inconsistent and is likely to be affected by a change in stress levels prior to the session

stability in line with occupational therapy input. This is supported by Bobath's (1990) premise that one cannot impose normal movement on abnormal muscle tone. He suggested that once the muscles of core stability were engaged, this would lead to increased pelvis and shoulder girdle stability, which in turn would lead to a greater ability to engage with more complex and fine motor tasks.

The intervention

The OT noted (see Table 1) that John's facility for body awareness and tactile discrimination increased after exercises that engaged his muscles of core stability and provided enhanced sensory input. It would therefore be appropriate to include these activities prior to engaging in a dressing activity. She had also stated that he derived enjoyment from these activities.

The Residential Care Team reported that morning routines were challenging for John, therefore they found it more beneficial to work on John's dressing skills as he was preparing for bed, when he was in a more positive frame of mind. In the context of the intervention, this timing may also mean that staff have more time to set up positive interactions with him prior to dressing for bed.

Dressing for bed routine

Planned into the routine are:

- Communication about the proposed sequence of events through use of his visual 'first/then' schedule. He would also be capable, supported by PECS, of making a choice of proprioceptive activity.
- Opportunities to increase body awareness through proprioceptive feedback. It is important that, prior to settling down, the activities are calming. The OT suggested he might enjoy such activities as sensory massage (e.g. using a rough wash mit or wooden rollers, etc., to massage forearms and hands or lower legs and feet), time spent under a weighted blanket, use of an electric toothbrush, etc.
- Opportunities to engage his muscles of core stability and increase his body awareness through replicating activities from the OT/SLT's session. Introduction of a gym ball into his bedroom and replication of part of the OT/SLT's session prior to changing clothes. First by engaging with him in a calm bouncing activity on the gym ball (which he enjoys in the context of the OT/SLT's session), and then, while he is seated on the ball, encourage putting away laundry piece by piece on shelves at different heights. He would thus need to stretch to different heights and angles, and increase his range of movement by perhaps picking some laundry up from a pile on the floor and turning to staff to collect other pieces to put away.
- Opportunities to interact positively with staff through activities he enjoys.
- Maximised opportunities to achieve by working on the aspect of dressing he finds easiest, e.g. removing clothing. Having enhanced his body awareness through these positive interactions with staff, and optimised his opportunity for success John could then be encouraged to undress with staff support.

Conclusion

The implications for John's quality of life of such a plan being implemented are short-, medium- and long-term. In the short-term, the positive gains are increased positive interaction with staff leading to enhanced self-esteem. Medium-term achievements include continuing, incremental improvement in posture, fine motor skills attainment – again leading to increased success and self-esteem. Long-term gains are sustained improvement in fine motor skills and a possible reduction in the exaggerated lumbar lordosis, and hence in the likelihood of developing physiological complications due to back strain through lordosis.

Acknowledgement

We would like to record thanks to John's Residential Care Team Leader, Class Teacher,

Speech and Language Therapist, Support Workers in all departments, John himself and his mother, who generously and variously gave time, support, advice and opportunity to spend time with John in the course of preparing and writing up this research project.

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Di Foxwell

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Articles can be long or short and they are welcomed from carers or professionals alike – we value YOUR experience and views. Please contact us if we can help you in any way. If you have any picture or photos to include we would love to see them (providing we have permissions).

Vol. 18 No. 2 Issue 54

Born too early? Implications for low-birth weight infants and their families

By Barry Carpenter, Chief Executive, Sunfield
Professor of Early Childhood Intervention, University of Worcester

With technological progress and developments in medical practice, the survival rates of neonates are increasing (Emsley et al., 1998; Woodward et al., 2004). A significant proportion of these children will be born with major disabilities and will require the lifelong support of professional services (Carpenter, 1999). A journalist writing in *Community Care* (2005) commented:

Improved diagnosis, better survival rates, and a growing incidence of complex disabilities such as autism have resulted in a 62% increase in the number of disabled children living in the UK.

Professionals will need to plan ahead, to address the challenges to family life, to explore new ways of intervening in order to improve life for the next generation of children with learning difficulties and their families, and to work with them to achieve their aspirations.

Survival rates of neonates

Emsley et al. (1998) have particularly focused on the survival rates of premature/very low-birth-weight infants as an upward trend reported in many Western countries. Their study showed that during 1984–1989 and 1990–1994, the survival of preterm babies had improved from 27% to 42%. These figures pale into insignificance when compared with the outcomes of the EPICure study (Marlow et al., 2005). The population of the study, established in 1995, were infants born in the UK and Ireland at less than 26 weeks gestation, of which 80% now survive. Woodward et al. (2004) in New Zealand gave a survival figure of 90% for the same population.

The impact of premature birth is explained in Table 1.1 below.

Gestation at Birth	23 weeks or less	24 weeks	25 weeks
No disability	12%	14%	24%
Mild disability • Low normal IQ scores • Wear glasses/have squint • Mild hearing loss • Minor neurological abnormalities	25%	36%	35%
• Moderate disability • Moderate learning problems • Cerebral palsy, but walking • Hearing aids • Some vision deficit	38%	22%	22%
• Severe disability • Severe learning problems • Cerebral palsy, not walking • Profound deafness • Blindness	25%	29%	18%

Table 1.1: The percentage of children with different degrees of disability with examples of the types of problem in each classification under each category (from the EPICure study

A follow-up study, when children from the EPICure group were six years old, saw assessment taking place on 80% of the original cohort. These assessments yielded the outcomes depicted in the diagram below (see Figure 1.2).

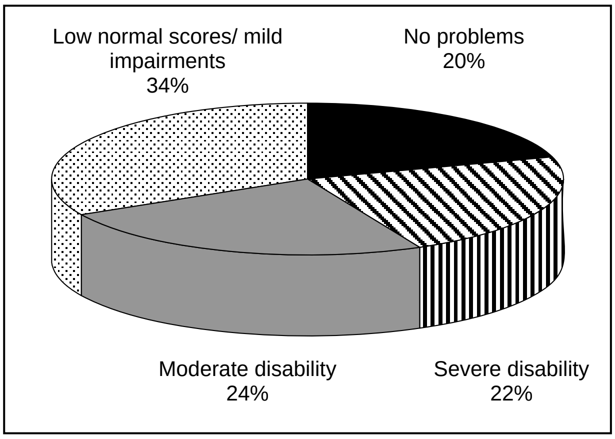

Figure 1.2: Proportion of children with disability out of 241 children seen at six years by comparison with their classmates (Marlow et al., 2005)

Boys seemed to fare much less well than girls, being more prone to disability and having lower scores in all major developmental test areas. This difference cannot be explained, but it has been found throughout the study from its first results in the period after birth.

Perry and Pollard (1998) vividly describe, through their research, the impact of traumatic birth and early care processes on the infant, and how such experiences will shape the brain and its perceptions and reactions for years to come. The 'emotional security' described by Robinson (2003) as being a crucial component of a baby's psychological development is severely disrupted through a birth which requires intensive and invasive medical treatment.

A disturbing piece of research (Fitzgerald, 1998) from University College, London, discovered that babies' sensory systems have a unique, pain-signalling mechanism which disappears as they grow older and that newborn children feel pain longer and more sensitively.

In premature babies, the mechanism that 'dampens down' the pain messages does not work properly. It is therefore essential to consider whether the impact on the sensory pathways subsequently compromises their effectiveness as learning channels for these children (Champion 2005). Intense ethical debates arise around these babies' fragile lives. The High Court case of Charlotte Wyatt highlighted the divergence between medical judgments and parental opinion, leading one commentator to claim, 'Keeping "miracle" babies alive is a disaster for all' (Marrin, 2004). Traynor (2004) has reported that mercy killings are a regular feature of medical practice in Holland. Clear guidance is needed to end these dilemmas for the medical and legal professions. Charlotte Wyatt's survival into 2005 has called into ethical debate the original 'Do not resuscitate' order from the High Court (Templeton, 2005).

At the heart of this complex maze of medical activity lies a family, traumatised by the birth of one of its children. This mother's words describe the human pain and anguish:

…on the first visit they gave me too much information… It's great there's so much out there, but it can be too much to absorb. Even if your child doesn't have a disability, you're adjusting to your life with a baby – you've just given birth, your lifestyle has changed, you're exhausted and, on top of that, you have to come to terms with something you hadn't anticipated. There is a danger of being bombarded. A Mother (Foundation for People with Learning Disabilities, 2005)

Assisted conception

Throughout the world, there is an upward trend in the rate of multiple births, particularly in countries where the treatment of infertility is available (Mitchell, 1998). Russell (1998), reporting the preliminary findings of a Medical Research Council study, noted that 70% of multiple births due to in vitro fertilisation resulted in some form of disability. Human Fertilization and Embryology Authority (HFEA) figures (HFEA, 2003) suggest that the incidence of cerebral palsy in twin births is five times greater than the national average for single babies and, in triplet births, eighteen times greater. Hence, some families may have one, two or more children with disabilities. In a similar domain, the role of genetic information (Barr and Millar, 2003) is influencing the coping strategies of parents who have a child with disabilities. They state:

When a child has a disability parents often seek answers as to the origins and nature of the condition as part of the adaptation process. For some parents this will result in genetic investigation and could lead to the provision of personal genetic information about the child and parents.

Ironically, some disabled children may themselves be victims of improvements in neonatal and medical care. A review of 25 studies of babies born after assisted conception (Helmerhorst et al., 2004) notes the greater risk of perinatal morbidity (and thereby possible later ill-health, disability or special educational needs). This study found the risk to be greatest in singleton pregnancies rather than in the multiple (twin) pregnancies most commonly associated with post-natal difficulties. Helmerhorst et al. note that:

> *25 years after the birth of the first baby conceived by in vitro fertilisation, our data draws attention to a number of challenges. Firstly, emphasis needs to shift, more than it has already, from achieving a successful pregnancy to achieving a successful outcome [for the child].* (Helmerhorst et al., 2004)

In effect, the increase in assisted conception raises new challenges for neonatal and other child health services. As Helmerhorst et al. observe, there is a need to narrow the gap in positive outcomes for children between assisted and other pregnancies. There are also implications for neonatal and Early Childhood Intervention services if we are likely to continue to see the survival of very small and sometimes very vulnerable babies.

Needs in families of premature babies

Champion (1998a,b) demonstrates how the mother (or care-giver) is the facilitator of brainstem maturation. She emphasises the importance of the first year of life in which the organisational pattern enabling the infant to cope with external stimuli is established. Those babies born prematurely, who spend their early weeks in an incubator separated from their mother for much of the time, may suffer consequences not yet understood.

In her more recent work, Champion (2003) has shown that 55% of mothers of preterm babies attending the Early Childhood Intervention programme at the Champion Centre were diagnosed with clinical depression. Post-traumatic stress disorder was also prevalent, displayed through irritability, outbursts, crying, numbed responses, traumatisation and experience of flashbacks.

It is increasingly recognised that fathers' emotional needs in relation to a disabled child often go unmet (Carpenter, 2002). Fathers, too, are an integral part of the difficult complexities that co-exist as families redefine themselves as parents of a vulnerable, low-birth-weight infant. Emotions experienced by both parents were:

- Terror
- Intense fatigue
- Guilt
- Anger
- Depression
- Jealousy
- Grief
- Frustration
- Impotence

The family system is also challenged by the birth of a preterm infant. The euphoria and atmosphere of congratulation is replaced by worry and anxiety for the health and survival of this vulnerable baby. Expectations will be derailed; concepts of 'parenting' may be restructured; wider family attitudes and perceptions may not be as expected; beliefs and cultural expectations may be challenged. There is a process of family adaptation over time, building a pattern around the child and its difficulties. Families have to devise new routines, and identify the parts that assist, sustain or hinder them.

Of course, these feelings may be part of the lifelong journey that these families will tread. The extent of cerebral injury may not be fully realised until the child realizes certain developmental milestones. The child, and its long-suffering family, may be subject to years of intense scrutiny. We must ask ourselves, as a responsible Society, do we have the systems, structures and resources in place to support those children (many of whom will have profound and multiple learning disabilities), and their families in their lifelong journey?

This article is an extract from a chapter by Barry Carpenter in 'Early Childhood Intervention: International Perspectives, National Initiatives and Regional Practice'.

Copies of this book are available from the Sunfield Research Institute. For further details please contact Tracey Deeley, Publications Officer: Tel: 01562 882253 Email: TraceyD@sunfield.worcs.sch.uk

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PMLD Network Email Forum (A Digest of Discussions) March 06 - June 06

Cheaper conferences/events for carers:

There was an appeal to all those who organise conferences and events to make them cheaper or free to unpaid carers. There was also a plea to professionals who are invited to bring carers along with them to the above, to do this more often.

A reply asked for information on how organisations can get funding for free places for carers.

A free event for unpaid carers was advertised around people with learning disabilities in Wandsworth on 20/07, 10am-3pm. It is called "The future is ours for the making" and looks at how carers can contribute to improving services. Call Ursula Haywood on 0208 725 3924 to book a place.

Advocacy for adults with PMLD

There was a request for information on the above topic. Two Mencap advocacy projects replied with details of how they work with this group. Newham Advocacy Project can be contacted by calling Anna McEwen on 0208 5522466. Cambridge Advocacy Project, (who work exclusively with people with PMLD), can be contacted by calling Sarah McKearney on 07876652047.

Health Action Plans and Transition

Information on doing health action plans with people in the transition period was requested along with examples of how health facilitators and children's services are working together. An article called "Improving the general health of people with learning disabilities", by Mike Kerr, was suggested as useful. (This can be accessed on www.choiceforum.org/improvinghealth.pdf).

Lack of day opportunities and short breaks

Much concern was expressed at the lack of these services for young people with PMLD in transition. There was a request for reports on similar circumstances in different areas. A report by the "Call Centre" on Further Education for students with special needs was recommended. This can be downloaded from www.scotland.gov.uk/Publications/2006/03/03103843/0 Children's hospices were suggested as an option for respite, apparently most have increased their age limit to 23 yrs. Examples of respite cuts in different areas without carers being consulted were given in another reply.

Meeting the health needs of people with learning disabilities

It was asked why parents and carers of people with learning disabilities are so often required to stay with people with learning disabilities during hospital stays. Oxfordshire learning disability partnership board said that usually someone who knows the person well is required to facilitate any complex communication. They also said they had met with their local acute hospital trust and established guidelines for staff. See forum for details of these, or you can find helpful resources from the Access to Acute Health Group on www.nnldn.org.uk/a2a/index.asp .

Also a representative from Diverse Identities pointed out that trainers in these circumstances should always include someone with a learning disability who can explode any stereotypes. There is a new resource for nurses and midwives in Scotland on working with people with learning disabilities http://snipurl.com/puf8 and a new RCN publication, "Meeting the health needs of people with a learning disability", (www.choiceforum.org/healthofpld.pdf). It was argued that staff extra staff should be provided so families are not relied upon to stay. Issues such as expressing needs and developing a routine for people to understand should be considered by staff.

There will be a conference on Patient Safety for People with Learning Disabilities on 19/09. Find out more on www.choiceforum.org/patientsafety.pdf .

Care Pathways

There was a request for examples of care pathways for children with PMLD from physiotherapists. Suggested was, "An Integrated Pathway for Assessment and Support", (see www.icwhatsnew.com).

Another suggestion was, "Family Led Integrated Postural Care Pathway", this will soon be available on www.nelh.nhs.uk .

Advice on choosing care services

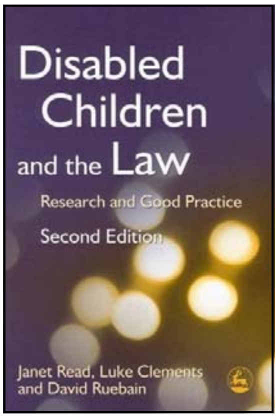
There is new advice available on choosing the best care services for a person's individual needs. The booklet "Choosing the right social care service for you" can be downloaded. See WWW.csci.org.uk/about_csci/press_releases/new_care_advice_will_help_me or http://snipurl.com/pejx

Transition

Best practice guidance is now available from the resource, "Transition: Getting it Right for Young People". See http://snipurl.com/pes7 .

The PMLD Network discussion forum (www.pmldnetwork.org) is run and maintained by the Foundation for People with Learning Disabilities, 7th Floor, 83 Victoria Street, London SW1H OHW. Tel. +44(0) 20 7802 0316. Fax. +44(0) 20 78020301. Email: nmorris@fpld.org.uk Website www.learningdisabilities.org.uk Registered charity No: 801130 Company Registartion No: 2350846

Reviews



Title:
Disabled Children and the Law Research and Good Practice

Author:
Janet Read, Luke Clements and David Ruebain

Publisher:
Jessica Kingsley Publishers

ISBN 1843102803

Pub Date: 2006 - 2nd Ed.

Cost: £19.99

This book is underpinned with the principles of equal rights for children with disabilities and anti-discriminatory practice. It attempts to explain how the law can be used to ensure appropriate services are available to meet the needs of children with disabilities and their families. It aims to promote good practice, involving children and their parents in decision making and explains the legal responsibilities of the local authority, health and other agencies.

It is written by a Reader from the University of Warwick, who lectures in social work to medical students and Solicitors (who have knowledge and experience in the Human Rights of people with disabilities).

It is organised in two parts; Part 1 covers research, good practice and the law and Part 2 offers legal resource material including sample letters and useful addresses.

The target audience is broad and includes parents and families, practitioners who work with children with disabilities, managers and policy makers.

The authors state that they found difficulties organising the book and have set it out around significant life events; early years, school years, transition into adulthood and living away from home. For this reason, it is not a book to read cover to cover, but a resource to dip in and out of, as required.

It is a very useful book that defines the legal obligations and powers of statutory agencies. It looks at the issues in broader terms and includes information that many families and practitioners may overlook or not be aware of. Included is information about the Human Rights Act 1998 and The Children's Act 1989 and 2000, housing, benefits and careers.

One of the main problems with a book like this is keeping it up to date with ever changing legislation; it may also prove a fairly daunting and depressing read for families. It is probably a book which is best placed in a library collection, resource centre or club.

I would personally recommend this as a reference book for any practitioner and their team who work with children with disabilities and their families. It would make an excellent resource for them to share with families during significant life events, and would hopefully help clarify what often feels a complex and confusing system for families to negotiate. In particular I think it would make an excellent source of information for students studying to work with children with disabilities and their families.

Julie Pill
Team Leader - Community Children's Learning Disabilities Nursing Team

Research

Norah Fry Research Centre,

A research project that will look at why people with learning difficulties self-harm has been awarded over £250,000 by the Big Lottery Fund.

The three-year project will be carried out by Bristol University's Norah Fry Research Centre and the Bristol Crisis Service for Women.

People with learning difficulties face a significant range of social disadvantages, barriers and exclusion that prevents them from participating fully in their communities. In particular, people with learning difficulties who self-harm are likely to face a more extreme degree of social exclusion.

"This will be the first time a study has actually asked people with learning difficulties about their own understandings of their self-harm and what would help them."

The research aims to understand the experiences of people with learning difficulties, and those who support them. The study will highlight how to better support individuals. For more information:

Dr Pauline Heslop
Pauline.heslop@bristol.ac.uk
Tel. 0117 331 0980

Report Back ....

Interconnections Conference: No More Bits and Pieces!

By Julia Dixon

This conference held earlier this year in Birmingham focused on exploring the integration of programmes and goals for babies and young children accessing pre-school services and settings and at school.

The snappy title to the day " No more Bits and Pieces " attracted people from all over the country and as ever it was good to be able to hear what is happening at a local level in different areas.
The conference was opened by Peter Limbrick, chair of Interconnections and founder of the one hundred hours experience.

The keynote presentation "Joining together: Integrated programmes in schools" was delivered by Penny Lacey, from the School of Education, University of Birmingham. Penny reminded us in her entertaining and informative presentation that there remain huge challenges in developing integrated programmes for children with complex needs in our schools. Penny talked to us about Alexander who has very complex needs and has no less than eight different people who work with him on a regular basis. She explored the challenges of keeping Alexander's needs at the centre and ensuring that his support is delivered in a more integrated way. It remains common practice in some special schools for children to be taken out of the classroom for their therapy, rather than using Foundation Stage Curriculum or other early years curriculum as a vehicle through which children's specific needs can be met in an integrated way.

Penny reminded us of the national drivers for integrated working, " Every Child Matters , The Ten Year Strategy for Children and the Common Assessment Framework " which all call for shared and joint assessments, joint planning and programme writing.

Penny left us with the challenge to make 'no more bits and pieces' a reality by working more closely together across services with the child and family at the centre.

Peter Limbrick then talked about " Collective Competence and Integrated Programmes in Early Support"

He reminded us of how babies and young children do not function in parts but as whole beings right from the start, any activity involves the whole child which is why play should be the vehicle through which programmes of therapy for babies and children are delivered.

Though his talk Peter explored " Systems Thinking" and how the child is a part of other systems for example the family, the centre, the school the community, and society in general. He called for a collaborative team around the child. "TAC" which would integrate holistic programmes and be delivered by a primary provider selected to deliver the programme as part of play /daily living activity. Peter argued that this would significantly reduce the number of practitioners the child has to cope with. The final part of his talk raised the suggestion of a code of practice to be followed by practitioners working with the family. He acknowledged that there implications for training and professional development.

The facilitated discussion groups before lunch gave delegates the opportunities to discuss one of two scenarios where there was a need for enhanced integration. Inevitably with delegates from all over the country it was interesting to learn about the very diverse practice which exists across so may healthcare trusts and education services and how far they were on the journey towards integrating services.

The first session of the afternoon was an opportunity for Nick Logan, consultant psychologist and senior manager on policy and practice in behaviour management at Sunfield residential special school and his colleague, Iain Chatwin, staff development coordinator at the school to share the integration between therapy and care at the school. They talked of how the structures now in place and working effectively had evolved over a period of time. Iain talked of how Sunfield had been compelled to change by the circumstances the school found itself experiencing during the 80's and 90's not least the changing needs of the children attending the school.

The children being referred to the school had very complex needs, many with severe autism and very challenging behaviour. In order to meet the needs of the children, the school has pioneered a behaviour management policy which embraces a range of strategies and therapies. The school offers a counselling service for use by its students.

The Sunfield assessment and outreach service is developing alongside the work which is taking place within the school offering assessment ,intensive support and consultancy to education authorities across the country.

Linda Fisher, Early Support Programme Coordinator for the multi agency resources centre in Essex (The MARC project) talked to us about the journey in Essex so far. It was most enlightening to hear Linda telling us how Essex had approached the challenge of integrated working and had identified five key areas of integration which need to be developed:

- Common understanding about collectively placing the child and the family at the centre of planning
- Common denominator for joined up planning
- Common use of language
- Common actions to change systems
- Common respect for each other's roles.

These had been drawn together into 3 important HOW factors through adopting the team around the child approach, sharing goals and developing one plan per child and family.

Linda summarised the project by sharing with us a model diagram which provides the mechanism for facilitating " No more bits and Pieces". Further information about the MARC project can be obtained by contacting Linda Fisher. (Linda.fisher2@essexcc.gov.uk)

Diann Davis from the National Portage Association concluded the programme for the day with a talk about the Portage home visitor programme and integration in early support. She gave us a detailed overview of portage and its history and shared with us the portage model of

- Working in partnership with parents,
- offering regular home visits
- Using structured teaching approaches
- Offering a child centred curriculum
- Monitoring supervising and managing
- Working very closely with other agencies.

Children and their families are kept at the heart of the intervention with children being helped to learn through a small step approach built around daily activities which are integrated into family routines and priorities . Further information about the Portage Association can be found by visiting the website www.portage.co.uk.

Mencaps Life Chances Team Conference: Profound and Multiple Change

By Lloyd Page

Last month members of Mencap's Life Chances Team ran a conference called Profound and Multiple Change. It was aimed at young people with Profound and Multiple Learning Disabilties. It was funded by three Learning Disability partnership boards in the South East Region of England.

This is a picture of Lloyd with Abbi Culham wearing a policemans hat complete with flashing light.

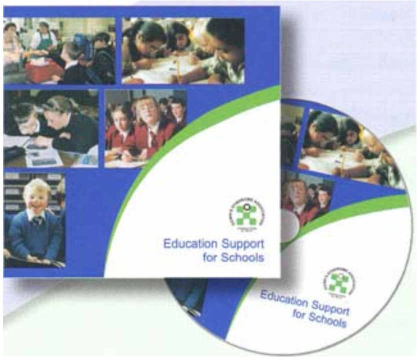
The people who planned the conference wanted to help families involved in local planning, they also wanted to show creative ways of working with people. I took part in the 3DTV workshop with Marion Janner and Flo Longhorn from Catalyst.

3DTV is all about making television much more accessible for people with learning disabilities.

The theme for the workshop was based on a famous television soap called Coronation Street we were given pictures and actors.

Other objects included a wedding ring, toy police car, champagne bubbles, to help everybody take part in watching the episodes.

NEWS, PUBLICATIONS AND RESOURCES



DSA Education Support CD ROM for Schools

The award-winning 'Education Support Pack for Schools' (mainstream and special school versions) includes: A guide to obtaining a statement of special educational needs Detailed practical information on including pupils in mainstream schools at primary and secondary level. There is also Information on:

- Reading
- Early years and starting school
- Numeracy
- Short term auditory memory
- Fine motor skills
- Transition from primary to secondary
- Adolescence and sex education
- Alternative accreditation
- Behaviour
- 14+ transition reviews

P Scales and assessment examples:

- QCA differentiated performance criteria for assessing progress and attainment below Level One of the national curriculum
- B Squared assessment tools to help with planning and target setting for pupils working below Level One of the national curriculum

Down's Syndrome Association
Langdon Down Centre
2a Langdon Park
Teddington
TW11 9PS

Tel: 0845 230 0372
Fax: 0845 230 0373
Email: info@downs-syndrome.org.uk

DOWN'S SYNDROME ASSOCIATION

Inspirational New Epilepsy Film Launched

Epilepsy Action has launched an innovative new film explaining how to manage epilepsy for people with moderate learning disabilities .

'Managing your epilepsy' is available on DVD and video with an accompanying booklet and was launched at this month's 'Managing Long Term Conditions 2006' conference in London.

A significant number of people with learning disabilities have epilepsy, yet there is a severe lack of accessible information about the condition. They are also more likely to have greater health needs than the majority of the population, but are less likely to seek help and receive treatment.

Epilepsy Action commissioned LBV Television to produce the stimulating film, presented by Dr Chris Steele, GP and resident doctor on ITV's 'This Morning', and aimed at people with moderate learning disabilities, their families and carers.

The film uses actors from the 'Mind the Gap' theatre group who have learning disabilities themselves. Featuring a series of short dramatised scenes to illustrate some of the daily issues faced by people with learning disabilities who have epilepsy, it helps viewers to understand the problems presented and encourages them to manage their own epilepsy.

A variety of locations are used to introduce the audience to the different environments and health professionals they may meet. The information is explained in clear and concise terms, and broken down into individual modules to allow the viewer to work at their own pace. An interactive quiz is included at the end, reinforcing the key messages and testing the user's understanding.

To request your copy of 'Managing your epilepsy' or any of Epilepsy Action's other resources, please contact Epilepsy Action on Free phone 0808 800 5050

NEW CODE OF PRACTICE ON DISABILITY DISCRIMINATION

A new code of practice from the Disability Rights Commission is laid before Parliament today for its consideration, giving guidance on the application of the Disability Discrimination Act (DDA).

Anne McGuire, Minister for Disabled People, warmly welcomed the "clear advice and guidance" in the new code, saying:

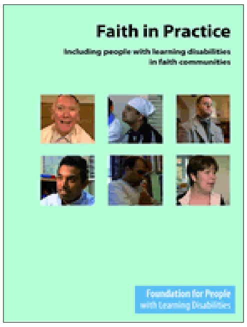
"The Government believes that clear and accessible advice and guidance for those with rights and responsibilities under the DDA is important. The duty of reasonable adjustment will be extended to those who let or manage rented premises, and to common hold premises. But this does not include any duty on those who let or manage premises to adjust physical features of the dwelling itself. Landlords cannot unreasonably withhold consent to a request from a disabled tenant or occupier for a disability-related improvement to certain rented dwelling houses. The duty of reasonable adjustment will be extended to private members clubs with 25 or more members.

The DDA also enables: introduction of a duty on public authorities to promote equality of opportunity for disabled people; the transport exemption from Part 3 of the DDA 1995 to be lifted for different vehicles at different times and to differing extents; an "end date", of no later than 1 January 2020, to be set by which time all rail vehicles will have to meet accessibility regulations, those regulations to be applied to refurbishments and other measures on rail such as the introduction of compliance certification and decriminalisation of offences; reciprocity for disabled persons' parking badges issued in other countries; and the duty of reasonable adjustment to be extended to local authorities and the Greater London Authority in respect of their disabled members.

There are around 10 million people in Britain covered by the DDA. The DDA defines disability as a physical or mental impairment which has a substantial and long-term adverse effect on the ability to carry out normal day-to-day activities.

There are 6.9 million disabled people of working age (16-59/64) in Great Britain accounting for nearly a fifth of the working age population; 50% of disabled people of working age are in work, compared to 81% of non-disabled people (the employment rate of all employees is 75%); the income of disabled people is, on average, less than half that of non-disabled people.

New film highlights how faith communities can support people with learning disabilities



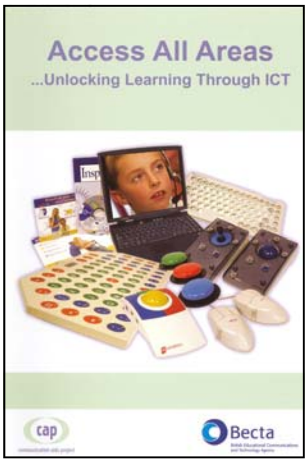
On Thursday 8 June, the Foundation for People with Learning Disabilities premiered their new short film at the Globe Theatre in London. Religious leaders from major faiths, people with learning disabilities and their supporters were invited to the screening of ***Faith in Practice***, which highlights how faith communities can include people with learning disabilities.
A team of people with learning disabilities were involved in the production of the film, which examines how the Sikh, Muslim, Christian, Jewish and Hindu faiths can support people with learning disabilities. Faith leaders and people with learning disabilities feature in the film.

Hazel Morgan, Co-Director of the Foundation for People with Learning Disabilities said; "Many people with learning disabilities value being part of a faith community but rarely get the support they need to fulfill their spiritual or religious needs, a basic human right. We hope this film will encourage faith communities to involve people with learning disabilities more."

Faith in Practice is available in ***DVD and video format***. Copies are priced £12.50, but are free to people with learning disabilities and family carers. The film is part of the ongoing work into religion and spirituality by the Foundation for People with Learning Disabilities'. For more information please visit www.learningdisabilities.org.uk or telephone 020 7803 1100.

Do you facilitate Person Centred Plans?

If so you may be interested in our MAP & PATH Templates which are available on cd roms. The MAP and PATH templates are designed to produce professional looking plans by inserting your own information from the planning session onto pre designed pages/slides. We find the person who's plan it is enjoys inserting the info or using the CD rom to reflect on what has been recorded. For more information please visit our web page www.supported-living.org



Access All Areas: Unlocking Learning through ICT

CAP is designed to help pupils who have a significant difficulty in communicating with others.

It seeks to give support to pupils who have difficulty in:

>understanding language
>communicating verbally
>using written communication

All pupils have a right of access to the curriculum. Fortunately, there are a range of technological aids which can help them do this, and the principle aim of CAP is to identify equipment which will meet the needs of individual pupils.

This CD provides an introduction to assistive technology and can serve as a resource in raising the awareness of the ICT support available to pupils with communication difficulties.

It is hoped that the information on this CD will help teachers, education and health professionals and parents in enabling pupils with communication difficulties to realise their potential.

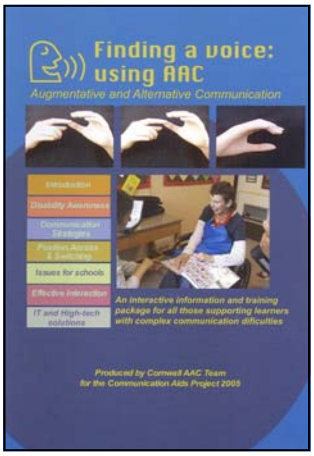
For further information please contact us:

Tel: 02476797173
Web: http://www.becta.org.uk/cap
Email: cap@becta.org.uk

A new 'tsar'

A new 'tsar' has been appointed at the Department of Health to help lead government policy on the lives of people with learning disabilities.

Nicola Smith, 43, from West Sussex, will work alongside the current National Director for Learning Disabilities, Rob Greig.



Finding a Voice: Using AAC

Finding a Voice was produced by the AAC Assessment Team, who provide assessment for children who might benefit from technology to support their communication needs.

Initial funding for the materials came from the SEN Small Programmes Fund and production was in collaboration with the Communication Aids Project (CAP).

This project, which is funded by the OfES, operates in partnership with schools and LEAs, and supports pupils who have significant communication difficulties by funding assessment, ICT equipment and training.

For more information see the CAP link www.becta.org.uk./cap

Family Led Integrated Postural Care Pathway

The pathway has been developed in the UK but is also being introduced in Australia and there are plans to have it up and running by the end of this year in Japan. The care pathway outlines roles and responsibilities and objective outcome measures that can be used to monitor progress. The individual and their family, who provide the vast majority of care, report when and why things don't go to plan (variance reporting) at each stage. This gives everyone a structure / plan and makes difficulties faced by those on the pathway easily identifiable. The variance reporting can be plotted to see what's going on across the country, common difficulties, and possible future policy development. On the other hand it also assists services who are providing high quality provision – prompt identification of need, quality assured training, efficient equipment provision (wheelchair, sleep system, orthotics, alternative seating etc) measurement of body symmetry and ongoing support – to demonstrate such good practice. The Family Led Integrated Postural Care Pathway – it will be on the National Electronic Library (www.nelh.nhs.uk) soon.

Issue 3 May/Jun 2006
£3.75 UK (£6.00 Overseas)
Insight
RNIB
Helping children and young people live and learn with sight problems
Access to learning
- Early braille literacy
- Searching the Internet using Jaws
- Using ICT to play, communicate and learn

Plus
- Curriculum Bitesize Graphs and diagrams
- Promoting continence

Insight Magazine

Insight magazine - RNIB on the education of children and young people, including those with additional or complex needs

Insight is a bi-monthly magazine dedicated to providing inspirational and practical information on the education of children and young people, including those with additional or complex needs. Insight is packed full of useful ideas, personal stories and help and advice from teachers, parents and leading experts brought to your door six times per year.

UK customers
Tel. 0845 702 3153
Email. cservices@rnib.org.uk

Overseas customers
Tel. +44(0)1733 37 54 00
Email. exports@rnib.org.uk

Campaign: *A Big Conversation* for Adult Learners Week

'A Big Conversation' is about asking people where they think the money to pay for adult education should come from.

We think it is really important to hear what you have to say. We have heard that a lot of courses for people with learning difficulties are being cut.

Adult learning is really give people the opportunity to get out and meet new people and make friends , to help you learn about things that you are really interested in .

Please let us and your MP know what you think by joining in the Big Conversation. You can send your replied to us at the bigconversation@niace.org.uk and copy your response to the Health and Disability Equality Team at caroline.law@niace.org.uk.

For more information about the campaign http://www.choiceforum.org/accessibleconv.doc

NHS Scotland: Getting It Right Together

This training resource on learning disability, has been written for nursing and midwifery practitioners in Scotland. It contains four units of study, six narratives and a video, which will support approximately twelve to fifteen hours of learning on a range of issues that relate to learning disability. The material has a number of intended learning outcomes for your own professional development. After studying this material you should be more knowledgeable and confident in working with people with learning disabilities and responding to their health care needs.

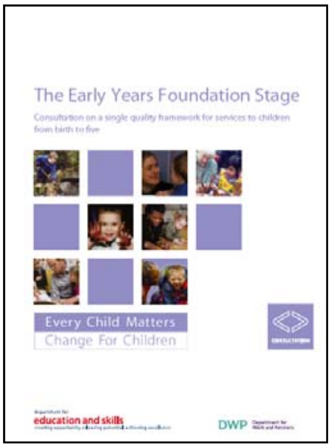
To view the materials see http://snipurl.com/puf8 and click on the links to download the learning material:

Unit 1 - The nature of learning disability and its causes (PDF, 337K, 1.35 mins)
Unit 2 - A brief history of learning disability (PDF, 148K, 42 secs) Unit 3 - The importance of inclusion and healthcare for people with learning disability (PDF, 156K, 44 secs)
Unit 4 - Working with people with learning disability (PDF, 103K, 29 secs)
The narratives (PDF, 80K, 22 secs)
Resources (PDF, 50K, 14 secs)
Staff needs: self-assessment (PDF, 26K, 7 secs)
Personal resource (PDF, 17K, 4 secs) - this is a blank page for use if the learning resource is downloaded and printed Just ordinary people (WMV, 32.8M, 19 minutes in length)

Social Care Institute for Excellence (SCIE) Clear guidance to help protect vulnerable adults

The Social Care Institute for Excellence (SCIE) and Department of Health have published new guidance for social care workers on making referrals to the Protection of Vulnerable Adults (POVA) list in England and Wales . The online guide – Making referrals to the Protection of Vulnerable Adults scheme –explains the process of referring regulated care workers and adult placement carers who are considered guilty of causing harm to a vulnerable adult. It covers each stage of the referral – from defining abuse and recognising harm, to providing evidence to support a referral. For more information: www.scie.org.uk/

Consultation on the Early Years Foundation Stage (EYFS)



The Early Years Foundation Stage

Consultation on a single quality framework for services to children from birth to five

Every Child Matters
Change For Children

1. This document invites comments on a draft of the *Early Years Foundation Stage* (EYFS), which is due to come into force in September 2008. The EYFS will be a single framework for care, learning and development for children in all early years settings from birth to the August after their fifth birthday. Building on the existing *Curriculum Guidance for the Foundation Stage*, the *Birth to Three Matters* framework, and the *National Standards for Under 8s Day Care and Childminding*, the framework aims to increase coherence, provide a flexible approach to care and learning and raise quality throughout the Early Years Sector. It is intended to play a key role in improving the life chances of all children, regardless of their family circumstances, by setting a clear expectation of the care, learning and development they will receive, whatever the setting they attend.

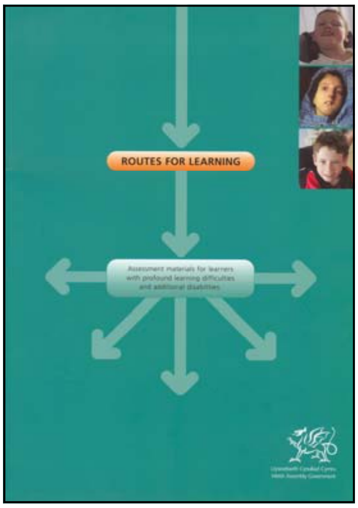
2. Development of EYFS has been taken forward in partnership with key stakeholders and delivery partners, across the maintained private, voluntary and independent sectors. A wide range of events have been held over the last year, with groups of practitioners, heads of centres, headteachers, local authority and further and higher education staff and national early years organisations. A dedicated email address has enabled wider participation and a range of settings in four local authorities have been funded to carry out specific consultation with parents and children.

3. The majority of feedback has been positive. Practitioners particularly have recognised, and welcomed, content from both *Birth to Three Matters* and the Foundation Stage contained within the learning and development grids, while recognising the advantages of bringing the material together in a single framework.

4. Many settings are already delivering *Birth to Three Matters*, the Foundation Stage and the *National Standards for Under 8s Daycare and Childminding* successfully. They will recognise much of what is in EYFS from those earlier documents. We hope EYFS will represent a logical development, bringing together and simplifying the learning and development and welfare requirements and ending the sometimes unhelpful distinction between care and learning and between birth-to-three and three-to-five provision.

5. We have retained principles, pedagogy and practice from *Birth to Three Matters*. Each of the Areas of Learning and Development reflects the 'stepping stones' approach of the Foundation Stage, but is set out with icons and headings which *Birth to Three Matters* practitioners will recognise.

From The Welsh Assembly: Routes for Learning



ROUTES FOR LEARNING

Assessment materials for learners with profound learning difficulties and additional disabilities

The Routes for Learning materials will support schools in assessing the early communication and cognitive skills of learners with profound learning difficulties and additional disabilities whose progress will not necessarily be hierarchical. The materials meet the very individual needs of these learners by showing a range of possible learning pathways.

These materials have been designed to be used across the curriculum with learners of all ages and may be a resource for teachers, support staff, school managers, LEA advisory staff and trainers in Initial Teacher Education and Training (ITET) institutions.

The pack Contains:

Routes for Learning - Assessment booklet
Routes for Learning - Additional guidance
Routemap: example sheet
Routes for Learning DVD

Copies of this pack are available by contacting: 0870 242 3207

INTERCONNECTIONS
ELECTRONIC BULLETIN
ABOUT CHILDREN WITH DISABILITIES / SEN

JULY 2006

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7. The Child Bereavement Trust Conference,
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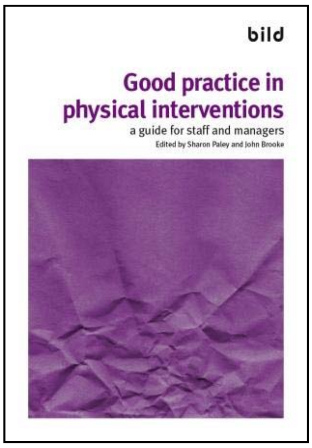
25. I CAN's Talking Point Website

If you would like a copy of Interconnections Electronic Bulletin please contact:

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

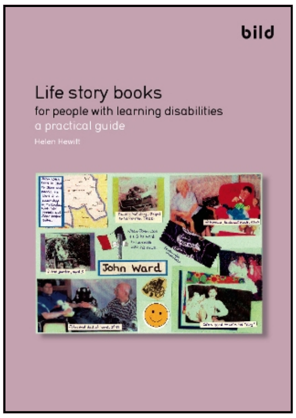


Author (s):	Edited by Sharon Paley and John Brooke
Publisher:	BILD
ISBN:	1904082742
Pub Date:	2006
Price:	£20.00

Good Practice in Physical Interventions: a guide for staff and managers

The first handbook for staff and managers on good practice in physical interventions draws together practical guidance from some of the UK's leading physical interventions trainers and experts.

The handbook covers a wide range of issues including: legal and ethical issues, abuse, misuse and poor practice and risk assessment using physical interventions in schools and children's services

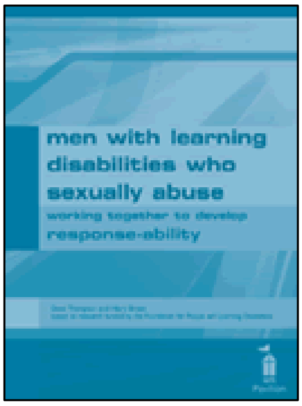


Author:	Helen Hewitt
Publisher:	BILD
ISBN:	1904082769
Pub Date:	2006
Price:	£16.00

Life Story Books for people with learning disabilities a practical guide

A life story book is an account of a person's life, including stories and memories of past events and relationships – all the kinds of experiences that make us who we are.

In addition to helping the person with learning disabilities, these books also enable others to see beyond the 'client' identity and appreciate that each person has a unique life history that sets them apart from other people.



Author:	David Thompson, Hilary Brown
Publisher:	Pavilion Publishing (Brighton) Ltd
ISBN:	1841961353
Pub Date:	2006
Price:	£95.00

Men with learning disabilities who sexually abuse

This revised and updated edition of ***Response-ability*** has been written primarily for direct care staff and their managers in services for people with learning disabilities, who have responsibility for working with men whose sexual behaviour challenges services or impinges unacceptably on other service users, staff or members of the public. It offers a reference to guide workers to find shared solutions to problems, and to find safe ways of working with and for individuals. This is not a book about specialist treatment programmes or about legal complexities.

Author:	Department of Health, Child Health and Maternity Services Branch
Publisher:	
Pub Date:	2006
Price:	FREE

Transition: getting it right for young people :Improving the transition of young people with long term conditions from children's to adult health services

This Good Practice Guide aims to show that the handover from children's and young people's services to adult services should be planned and managed as a process. The Guide suggests how this can best be accomplished in the context of the evidence base.

To view Transition: getting it right for young people go to: http://snipurl.com/pes7

Short Courses and Conferences *2006*

Providers Details

BILD

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

Catalyst Education Resources Ltd

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

Concept Training

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

Consent

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

EQUALS

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

Sunfield PDC

Clent Grove, Clent,
Nr. Stourbridge,
West Midlands DY9 9PB
Tel. 01562 883183
E-mail: Sunfield@sunfield.worcs.sch.uk
Website: http://www.sunfield-school.org.uk/Training/Summer2006.htm

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

September

Date: 8th
Title: Using Intensive Interaction
Provider: Concept Training
Location: DUBLIN, Red Cow Hotel
Contact: (See Providers Details)

Date: Thursday 14th
Title: Children with special needs: Coordinating education, health and social care
Provider: Royal Society of Medicine
Location: Bournemouth University, Talbot Campus
Contact: RSM Administration: Simon Timmis Tel: (+44) (0) 20 7290 2980 For further information and booking go to http://www.rsm.ac.uk/academ/A10_children.htm

Date: 14th
Provider: Concept Training
Title: Using Intensive Interaction
Location: LONDON, The Ibis Hotel Euston Station
Contact: (See Providers Details)

Date: 18th
Title: Physical Education—an introduction to Sherbourne Developmental Movement
Provider: EQUALS
The course is designed for teachers and support staff. The workshop numbers will be limited to 30 places due to the practical nature of the day.
Location: Fairfields School, Northampton
Contact: (See Providers Details)

Date: Tuesday 19th
Title: First National Conference on 'Patient Safety for People with Learning Disabilities'
Provider: Joint NPSA/RCPSYCH event
Location: London
Contact: For more information and enquiries please contact our Programme Administrators on 020 7977 6652/57 or visit www.rcpsych.ac.uk

Date: 20th
Title: Building Community Networks
Inspiring one another to include people with learning disabilities in our communities
Provider: Foundation for People with Learning Disabilities
Location: BMA House, Euston, London
Contact: To book a place on the conference, or for more information contact:
Gillian McEwan – Marketing Events Officer
Foundation for People with Learning Disabilities
Tel: 020 7803 1159 / Email: conferences@fpld.org.uk

Date: 25th
Title: *Joint Conference with National Drama*
Drama, Storytelling & Special Needs
Provider: Sunfield PDC
Led by: Dr Nicola Grove, City University &
Dr Melanie Peter, Anglia Ruskin Univ.
Contact: (See Providers Details)

Date: 27th
Title: An Introduction to Widgit Symbols (a hands on course)
Provider: Sunfield PDC
Led by: Jan Cook, IT Training Officer, Sunfield
Contact: (See Providers Details)

October

Date: 5th
Title: Making Sense of 'P' Levels
Provider: Concept Training
Location: SHEFFIELD, Sheffield Park Hotel
Contact: (See Providers Details)

Date: 6th
Title: Personal Communication Passports
Provider: Sunfield PDC
Led by: Sally Millar, Co-ordinator for C.A.L.L.
Contact: (See Providers Details)

Date: 11th & 12th
Title: Advanced TEACCH Course – Advanced Structured Teaching Approaches
Provider: Sunfield PDC
Led by: Mary Beth van Bourgondien, Clinical Director, Raleigh TEACCH Centre N.C., USA & Celeste Carter, TEACCH Centre N.C., USA
Contact: (See Providers Details)

Date: 11th
Title: Integrating and implementing person-centred approaches
Provider: Pavilion Publishing
Location: ORT House Conference Centre, London
Contact: For programme and booking form see: http://www.pavpub.com/pavpub/conferences/showfull.asp?Conference=569 Alternatively try: http://snipurl.com/s4f4

Date: 12th
Title: Making Sense of 'P' Levels
Provider: Concept Training
Location: WOLVERHAMPTON, Jennie Lee Centre
Contact: (See Providers Details)

Date: 16th
Title: Using Intensive Interaction
Provider: Concept Training
Location: READING, Reading Education Centre
Contact: (See Providers Details)

Date: 20th
Title: Physical Education—an introduction to Sherbourne Developmental Movement
Provider: Equals
The course is designed for teachers and support staff. The workshop numbers will be limited to 30 places due to the practical nature of the day.
Location: Hadrian School, Newcastle
Contact: (See Providers Details)

November

Date: 2nd
Title: Teachers Awareness Day – Perspectives in Autism
Provider: Sunfield PDC
Contact: (See Providers Details)

Date: Friday 3rd
Title: Good SLD Practice – *what works?*
Location: Manchester Conference Centre
Provider: BILD
Manchester
Contact: For details of other BILD conferences please contact Liz Howells on
Telephone: **01562 723025**
Fax: **01562 723029**
E-mail: **learning@bild.org.uk**
or see the BILD website:
www.bild.org.uk

Date: 3rd
Title: Talking to Families, Listening to Families
Provider: Sunfield PDC
Led by: Barry Carpenter, Chief Executive, Sunfield &
Sally Conway, Head of Family Services, Sunfield
Contact: (See Providers Details)

Date: 7th
Title: An Introduction to Makaton (basic sign language)
Provider: Sunfield PDC
Led by: Linda Hardy & Jan Millward, Makaton Trainers, Sunfield School
Contact: (See Providers Details)

Date: 8th
Title: Specialist Curriculum for Pupils with PMLD – **MIDLANDS LAUNCH**
Provider: Sunfield PDC
Led by: Richard Aird, Head Teacher, Barrs Court Special School &
Karen Aird, Independent Consultant in SLD/PMLD
Contact: (See Providers Details)

Date: 9th
Title: Approaches to Promoting, empowering, Unlocking and Discovering the Potential of Pupils with complex Needs
Provider: EQUALS
Location: The Bonnington Hotel in Bloomsbury, 92 Southampton Row, London
Contact: (See Providers Details)

Date: 13th—15th
Title: 3-Day SLD Induction – Challenging Behaviour
Provider: Sunfield PDC
Contact: (See Providers Details)

Date: 16th
Title: Using Intensive Interaction
Provider: Concept Training
Location: LEICESTER, Forest Lodge Education Centre
Contact: (See Providers Details)

Date: 16th
Title: S.D.M 'Taster Day' Introductory Basic Course
Provider: Sunfield PDC
Led by: Cyndi Hill, Sherborne Consultant, Sherborne Association UK
Contact: (See Providers Details)

Date: Friday 17th
Title: Valuing Good Practice in Autism
Location: Marriot Hotel Newcastle
Provider: BILD
Contact: For details of other BILD conferences please contact Liz Howells on
Telephone: **01562 723025**
Fax: **01562 723029**
E-mail: **learning@bild.org.uk**
or see the BILD website:
www.bild.org.uk

Date: 17th
Title: Using Intensive Interaction
Provider: Concept Training
Location: LONDON, The Ibis Hotel Euston Station
Contact: (See Providers Details)

Date: 17th
Title: Sherborne@Sunfield; an adapted teaching approach for children with ASD
Provider: Sunfield PDC
Led by: Cyndi Hill, Sherborne Consultant, Sherborne Association UK &
Jotham Konaka, Teacher & Researcher, Sunfield
Contact: (See Providers Details)

Date: 22nd
Title: Switching to Communication
Provider: Sunfield PDC
Led by: Martyn Maltby, Deputy Managing Director, Liberator Ltd
Contact: (See Providers Details)

Date: 23rd
Title: The Mental Capacity Act - preparing for implementation
Provider: The Ann Craft Trust
Location: Nottingham
Contact: Further information and a booking form are available by contacting ACT on 0115 9515400 or by e-mailing at ann-craft-trust@nottingham.ac.uk

Date: 23rd
Title: Using Intensive Interaction
Provider: Concept Training
Location: WINCHESTER, Harestock Lodge Hotel
Contact: (See Providers Details)

Date: 27th
Title: Using Intensive Interaction
Provider: Concept Training
Location: CARDIFF, Express by Holiday Inn
Contact: (See Providers Details)

Date: 28th
Title: Making Sense of 'P' Levels
Provider: Concept Training
Location: LONDON, The Ibis Hotel Euston Station
Contact: (See Providers Details)

Date: 29th
Title: CONFERENCE – 35 years on: a celebration of development into the education of children with severe, profound and complex learning needs
Provider: Sunfield PDC
Keynote: Dr Phyllis Jones, University of South Florida, USA, + Various Speakers
Contact: (See Providers Details)

December

Date: 1st
Title: Using Intensive Interaction
Provider: Concept Training
Location: PORTSMOUTH, Express by Holiday Inn
Contact: (See Providers Details)

Date: 6th
Title: Making Sense of 'P' Levels
Provider: Concept Training
Location: NOTT/DERBY, M1 J24, Kegworth Whitehouse Hotel
Contact: (See Providers Details)

LONGER COURSES (with accreditation)

Updated April 2006

Master of Arts in Education
Understanding Severe and Profound and Multiple Learning Difficulties (EDUM028)
This module addresses the requirements of the Teacher Training Agency (TTA) National Special Educational Needs Specialist Standards. This accreditation is awarded to students completing the requirements for the three modules EDUM028, EDUM029 and EDUM040. This module is directly related to developing the competencies, knowledge, understanding and critical reflection of students who are, or planning to be Special Education Needs Teachers. The module adheres to the national TTA SEN Specialist Standards (Core and Extension Standards) and students are given opportunities and support to collate evidence to meet the standards.
For further Details: The University of Northampton. Tel: 01604 892192. E-mail: admissions@northampton.ac.uk

Certificate in Higher Education (CHESL): Supporting Learners with SLD/PMLD
During the course we will be looking in detail at the needs of learners who are known to have severe or profound and multiple learning difficulties. They may also have other additional or associated disabilities, such as physical or sensory impairments. The course will examine topics of both a theoretical and practical nature to provide students with a greater understanding about this group of learners. Together with a broad range of strategies and approaches that can be applied to practice. The sessions will include lectures, workshop activities, discussion and some visiting speakers.
For further Details: The University of Northampton. Tel: 01604 892192. E-mail: admissions@northampton.ac.uk

Postgraduate Professional Development *Multi-Sensory Impairment (MSI)*
The module aims:
To enable teachers to support the learning needs of pupils who have Multi Sensory Impairment (MSI in this context refers to pupils who have multi-sensory impairment and complex needs).

Opportunities will be provided for students:
1. To develop an understanding of definitions of MSI and how typical child development may be affected by multi-sensory impairment
2. To have an overview of relevant modes of communication for pupils who have multi-sensory impairment
3. To understand how specific theory and practice may be used as a basis for working with pupils who have multi-sensory impairment
4. To understand what needs to be assessed and why, when working with a child with MSI
5. To understand the roles of the other individuals involved with the child who has MSI including different models of collaborative working
6. These modules can count towards a post graduate award (Certificate, Diploma or Masters Degree)

The module will involve seven taught days, four school based training days (supported by a mentor) and school/institution based research . ***Applicants must have QTS***
This is a reduced fee - subsidised by the TDA grant funding, plus a top up £100 subsidy from EMSEN, reduces the cost to schools, services or individuals.
For further Details: The University of Northampton. Tel: 01604 892192. E-mail: admissions@northampton.ac.uk

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

It is primarily about the learning and development of children and adults with severe, profound and complex learning difficulties, particularly in the areas of cognition and communication. Education, in its broadest sense, is seen as a key topic but other areas covered include health, therapy and social care. An important central theme is multi-agency collaboration and course participants will be expected to develop and reflect on their collaborative work as part of course. All the course assignments are grounded in reflective and evidence-based practice and are driven by the individual professional development needs of participants.

The modules are as follows:
1. Understanding Learning Difficulties and Disabilities
2. Interventions for People with Learning Difficulties and Disabilities
3. Learning Difficulties and Disabilities: Communication and Behaviour
4. Working Together to Meet the Needs of People with Learning Difficulties and Disabilities
5. Learning Difficulties and Disaibilities: Life Long Learning
6. Either: Special Studies in Special Education or Practtioner Inquiry in Education

For further details: University of Birmingham Dr Penny Lacey, phone: 0121 414 4878 or email: p.j.lacey@bham.ac.uk

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

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

Students working on BPhil or Postgraduate Diploma programmes with some additional activities can, on successful completion, be recognised as meeting the requirements of the DfES for the mandatory qualification for teachers of children with multisensory impairments.
For further details: University of Birmingham Dr Liz Hodges on 0121-414 4873 or email: e.m.hodges@bham.ac.uk

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

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

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

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

Postgraduate Certificate/Diploma Profound Learning Disability and Multi-Sensory Impairment Programme
MSc Learning Disability and Multi-Sensory Impairment Programme
Programmes available by Distance Learning at The University of Manchester, School of Education
Programme Aims

- To provide an increased knowledge and understanding of children and adults who have complex needs and/or sensory impairments.
- To empower those directly concerned with this group to advocate for the rights of the individuals concerned.
- To enable this to happen by providing current information relating to cognitive, emotional, physical, sensory and social needs.

Programme Structure
Courses are delivered by Distance Learning over a period of 1 - 3 years (including an extra year of independent study for MSc. students undertaking their dissertation). The MSc and Postgraduate Diploma are also available full time (distance learning) over 1 year. The written materials are underpinned by a variety of Study School formats during this time. Student support is also provided by telephone contact with the academic tutors. There are no examinations and the course requires approximately 3-4 hours private study per week.
For further details: University of Manchester Janet Grimshaw, Phone: 0161 275 3463, Email: janet.grimshaw@manchester.ac.uk

BSc in Professional Practice (Learning Disability Pathway)

The School of Health & Social Care, University of Chester, BSc in Professional Practice (Learning Disability Pathway) - includes forensic, mental health/learning disability, challenging behaviour, older person with LD and epilepsy modules (plus others)
For further details: University of Chester
Telephone: 01244 511471 (Pat Palser), 511472 (Monica Davies) or 511473 (Ann Ashford)
Email: p.palser@chester.ac.uk, monica.davies@chester.ac.uk, a.ashford@chester.ac.uk

MSc in Advanced Practice (Learning Disabilities)
The School of Health & Social Care, University of Chester, MSc in Advanced Practice (Learning Disabilities) - includes generic modules in research and inter-professional working plus 3 LD specialist modules (socio- political themes in LD; developmental perspectives on LD; profound & complex needs).
For further details: University of Chester
Telephone: 01244 511471 (Pat Palser), 511472 (Monica Davies) or 511473 (Ann Ashford)
Email: p.palser@chester.ac.uk, monica.davies@chester.ac.uk, a.ashford@chester.ac.uk

Adults with learning disabilities who have significant and complex needs
The School of Psychology at the University of St Andrews offers a Post Graduate Certificate by open/distance learning: "Adults with learning disabilities who have significant and complex needs". This consists of four distance learning modules, chosen from six, and is available to staff with a professional qualification or a first degree.

- Challenging behaviour
- Mental health
- Offenders with learning disabilities
- Older people with learning disabilities
- Profound and multiple disabilities
- Vulnerability, victimisation and abuse

The next intake is October 2006.
The programme leads to further qualifications at Diploma and Masters level.
For further details: University of St. Andrews http://psy.st-andrews.ac.uk/people/personal/mc1/
Dr Martin Campbell email: mc1@st-andrews.ac.uk

Website mentioned in this issue	
The Handsel Trust	www.handseltrust.org
Interconnections	www.icwhatsnew.com
Portage in the UK	www.portage.org.uk
HFEA	www.hfea.gov.uk
National Network for Learning Disability Nurses (UK)	www.nnldn.org.uk/
National Library for Health (NLH)	www.nelh.nhs.uk
MAP and PATH templates	www.supported-living.org
Foundation for People with Learning Disabilities	www.learningdisabilities.org.uk
CAP	http://www.becta.org.uk/cap
Social Care Institute for Excellence (SCIE)	www.scie.org.uk/
PMLD Network Forum	www.pmldnetwork.org)