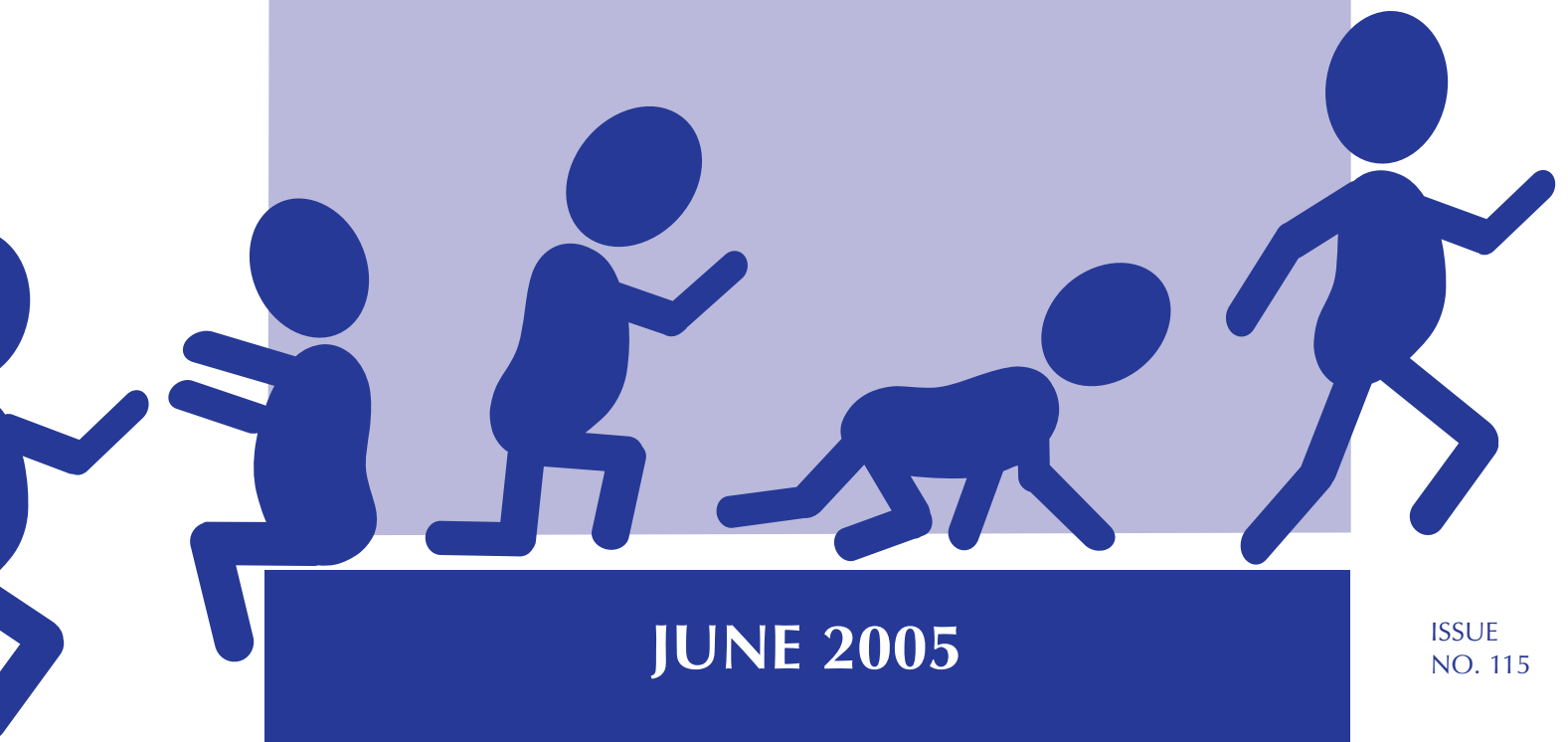


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Editorial	2
Letters to the Editor	3
ARTICLES	
Conference Edition	
Consent – the Welsh Vision <i>Geraldine Hastings LLM BSc (Hons) MCSP</i>	6
Perceived Efficacy and Goal Setting Systems <i>Carolyn Dunford</i>	9
Choice – Theory and Practical Application <i>Jenny Carroll MA MCSP</i>	11
Collaborative Practices in the community <i>Elizabeth Atter MCSP</i>	16
The Hopes and Choices of Parents <i>Caroline and Jemma Leech</i>	19
Poster Presentation	
Questionnaire Survey – Treatment Principles Used in the Management Of Cerebral Palsy <i>A L Bendall MCSP and D M Pickering MCSP</i>	24
REGULAR FEATURES	
APCP Matters	26
Research and Education	28
Regional Reports & Neonatal Clinical Interest Sub-Group Report	31
APCP Publications	34
Book Review	35
Here and There	36
Courses	37
APCP Research Register	39
Regional Representatives	inside back cover

The Editorial Board does not necessarily agree with opinions expressed in articles and correspondence, and does not necessarily endorse courses and equipment advertised

Editorial

My congratulations go to everybody on the Welsh Conference Committee who worked so hard to put together an excellent, relevant and stimulating programme. You even seemed to stage manage the weather for us, with many delegates making time for a run or a walk on the beach. This journal contains a taste for all of you of some of the excellent lectures that were presented in Swansea. Those of you who were not able to make it missed a treat. International lecturers gave interesting perspectives of some of the research going on in their parts of the world. Whilst home grown speakers shared their great depths of knowledge both with the practical workshops and with lectures that would have stood well on any international stage. It was also good and a timely reminder for us all to hear from a young service user and her mother.

I think very often when we are asked to do a talk or a lecture even at a very local level many therapists feel more than a little uncomfortable and daunted by the prospect. They feel that their expertise is clinical and that they are happy treating children and working with families and fellow professionals but to give a lecture that is a totally different skill - a skill that exposes us to others. However, it is this exposure that we as a profession of paediatric physiotherapists need. We are not good at selling ourselves. We do not go out and tell people what we do best. We do not share our best practice, so that it can be developed by our fellow professionals in all fields. If you get the opportunity to talk to groups of

service users, older school children, other professions and members of your team or service – take it with both hands and use it to promote paediatric physiotherapy.

It is also a good plan to look for feedback from any talk or lecture you give. Don't take the negative things as a personal criticism but rather tuck them away to use as a starting point when next you examine how it might be possible for you or your service to change practice. They might just provide you with a grain of an idea for doing something a little differently and occasionally point out a very glaring situation that needs addressing. Criticism is only destructive if it is taken or given in a negative way. If some comes in your direction, take it and try and use it positively.

Finally, on a different note, Congress with the CSP will be with us in October and APCP will be running a day of lectures on the Friday. So don't miss your chance, come along and take the opportunity to meet some of your APCP colleagues, network and share ideas. It can be great fun as well as informative and is often a chance to meet old friends and people that you haven't seen for a long time. Of course this year you will even have the opportunity to meet people that have not followed the same specialist career path as your self. I look forward to meeting some of you there. It is always really good to be able to put a face to a name that has only ever existed for me at the end of a telephone, letter or email.

Sally Braithwaite

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Dear Sally,

We are a small group of Physiotherapists and Physiotherapy Assistants working in a school for physically disabled children from nursery to 19 years of age.

Due to staff change and increased number of children to treat, the type of Physiotherapy treatment given to the children has to change from the more 'hands on' type of treatment to setting up of individual management programmes to be incorporated into all aspects of daily life.

This has already been implemented to a certain extent in the lower school but at present in the upper school, it is still very much the Physiotherapists doing the therapy and the Teachers doing the teaching.

In order to provide an efficient integrated Physiotherapy management programme for each child, as a team, we have to be able to work with both Teachers and Parents. We would therefore be very interested to hear from any other school based Physiotherapist who has recently had experience of implementing a Physiotherapy management programme in senior school for physically disabled children.

Yours sincerely,

Jane Hudson, Senior 1 Paediatric Physiotherapist
Marion Sleath, Senior 2 Paediatric Physiotherapist
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Dear Sally

I'm writing to make a general call to my colleagues in the field of paediatrics, who are practicing in the London area.

I myself have been working in paediatrics for over 10 years now and it would be true to say that the path of my career has been "atypical". However, this has, overtime, proven to be a blessing and I am now sufficiently confident in the approaches I have developed in the treatment of movement dysfunction (first in children with physical disabilities of neurological origin and in latter times, in the treatment of mainstream (muscular-skeletal) complaints in adults), to now seek to work in partnership with fellow physiotherapists.

I have specifically chosen to make my initial appeal to my colleagues in paediatrics, because I believe that knowledge of the origins and development of "healthy" or "normal" movement is essential for successful rehabilitation of movement dysfunction - at whatever age or time of life the dysfunction may occur. This view has led me to coin the term Movement Rehabilitation to best describe my approach and physiotherapeutic response to dysfunction and disability.

I am not at the moment making any specific offer, but I am keen to open up a forum of discussion and practical exchange with like-minded colleagues. I'm seeking to hear from any APCP member who has retained interest in treating adult musculo-skeletal complaints, who have some interest in complementary health techniques and who has a personal interest in the practice of yoga or a marital art.

Intrigued? Fit the bill?

Please do contact me at: kemi@bodyworksphysiotherapy.co.uk

Sincerely
Nkem Anagor Mcsp

Letters

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Dear Sally

I am a Community Paediatric Physiotherapist working with a 3 year old with paraplegia. I would like some advice from other members who have worked with a young child with spinal cord injury and could answer one or more of my queries:-

1. Can anyone recommend a rehabilitation centre that works with such young children?
2. What orthotics have been used to promote independent mobility and how successful were they (this child's recovery has plateaued at L3/4)?
3. Are there any rehabilitation programmes that physiotherapists have used?

Please reply to me at the address, telephone or fax shown above or via email at steven.swain@btinternet.com

Many thanks

Yours sincerely
Stephanie Swain
Senior 1 Community Paediatric Physiotherapist

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must be with the editor by

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A.P.C.P. Conference Wales 2005



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Swansea University

Thursday 31st March 2005
to
Saturday 2nd April 2005

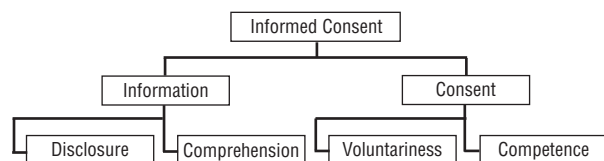
A Taste of Conference for All to Share

Consent - the Welsh Vision

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Introduction

The CSP Core Standards (CSP, 2005) and Rules of Professional Conduct (CSP, 2002) places an obligation on physiotherapists to seek their patient's informed consent for all interventions. Therefore, informed consent is pivotal in the physiotherapists' relationship with their patients. For paediatric physiotherapists, informed consent raises issues of confidentiality and consent to treatment, all of which must be dealt with in a format and language understood by the child, young person and their family.



The literature has identified various elements to the informed consent process (see above)¹. These elements are more complex when applied to children and young people. Information is an important part of the patient journey and a key element in the informed consent process and overall quality of patient experience. Improving consent procedures and providing better information for patients was a commitment in the NHS Plan (2000) and part of the recommendations of the Kennedy report into the Bristol Royal Infirmary (2001). There is also more evidence of the importance of information for patients provided in the Welsh Assembly Government's publication *'Good practice in consent implementation guide'* (WAG, 2002). Therefore, information for decision-making across the NHS has needed to be improved. Welsh paediatric physiotherapists are committed to improving communication with and the quality of information for their patients and carers alike. Sharing information brings the principles of consent and confidentiality together, by informing, protecting and providing choice for the patient. Welsh APCP members are currently piloting work on consent and information sharing; the history, objectives and progress of which are outlined below.

Where it began

Since 2003, the author and the CSP Policy Officer for Wales have co-facilitated the Consent Subgroup of the CSP Wales Paediatric Physiotherapy Network. The purpose of this group has been to develop an

All Wales paediatric physiotherapy strategy for the clinical implementation of the *'Reference Guide to Consent for Examination or Treatment'* (WAG, 2002). Prior to the publication of this guidance, Hastings (2001) conducted a survey investigating how paediatric physiotherapists in South Wales dealt with consent to and refusal of treatment in clinical practice. The findings reported that although there was evidence of good practice, particularly in relation to refusal situations, the area of practice which required improvement was the actual 'how and when' aspects of obtaining consent from child patients. There were also a number of political drivers which gave momentum to the project.

Political Drivers

Firstly, Devolution and the establishment of the Welsh Assembly Government (WAG) in 1999 led to job creation - the CSP Policy Officer for Wales. This in turn led to the formation of the CSP Wales Paediatric Physiotherapy Network. The purpose of this group was to assist with responses to relevant Welsh Assembly policy on behalf of the CSP Wales.

Secondly, the Welsh Assembly Government had implemented a programme *'Children First'*, to improve the quality of health and social services for children in particular those in care. These changes were brought about by the publication of the Waterhouse Report *'Lost in Care'* (2000), an investigation into child abuse in North Wales care homes. As a result, safeguarding the physical health and mental well-being of all children had become a top priority for governments across the UK. The report also paved the way for the appointment of the first Children's Commissioner for Wales.

As mentioned earlier improving information for patients including children was a commitment in the NHS Plan (2000) and one of the recommendations of the Kennedy Report (2001). In 2001, the Welsh Assembly Government published the *'Good practice in consent implementation guide'*, which was developed in response to the Kennedy Report, with the aim of assisting NHS organisations to promote good practice in the way patients are asked to give their consent to treatment, care or research (WAG, 2001).

The *Carlile Review* (March 2002) commissioned in response to *'Lost in Care'* and the *Review of Services for Children with Special Needs* gave paediatric physiotherapists in Wales an opportunity to highlight the issues of consent, child protection, and the provision of information to children/parents/carers. Government ministers heard of the poor facilities and access to information for those with visual and learning disabilities; those in need of translation facilities including into Welsh medium. In conjunction, there was also the issue of poor access for staff to appropriate IT and printing support to produce acceptable standard information; and also the poor

¹ Faden R & Beauchamp T L (1986) *A History and Theory of Informed Consent* New York: Oxford University Press

quality assurance monitoring and audit of information produced. In 2004, response to the *Safeguarding Vulnerable Children Report* gave paediatric physiotherapists another opportunity to stress the importance of communication and information sharing between professionals in the public and private sectors.

Reasons for Sharing Information

The overall aim of the project is to improve the informed consent process and share information about treatment modalities and activities throughout Wales, a view supported by the Welsh Assembly Government in their *'Informing Healthcare'* framework (WAG, 2003). The framework discusses the significant opportunities and benefits for healthcare professionals in general if they are able to communicate and share documents, messages and images easily regardless of location along with the ability to access information from a wide range of sources. The group also considered that sharing information would establish 'best practice' and in turn improve the provision and quality of paediatric physiotherapy services, as generally, resources are limited in terms of both time and finance. In addition, many paediatric physiotherapists are isolated working in rural communities. Consequently, sharing information would help the difficulties these physiotherapists have in keeping up to date with clinical developments. The sub group is also conscious of communication difficulties between paediatric physiotherapists in North and South Wales thus are keen to improve these relationships. There is also a need for information to be available in Welsh medium within the NHS (Welsh Language Act, 1993). Although the CSP is not a statutory organisation and thus is not obliged to provide bilingual information, its' members work in the NHS. It is good practice as a result for members to endeavour to do so. Another important indeed crucial reason for sharing information is to improve the overall quality of the child or young person's health care experience, to provide the patient with a choice and empower them to have a 'voice'.

The emerging objectives of the sub group were to:

1. Develop written guidance and training package around issues of informed consent in Wales.
2. Develop standardised therapy information leaflets to assist the informed consent process.
3. Standardise consent forms where possible in accordance with Welsh Assembly Government policy.

Consent Guidance Implementation Issues

The new consent to treatment forms were introduced in April 2002, with each NHS Trust adopting the model consent to treatment policy into their procedures by October 2002. The feedback from paediatric physiotherapists was that they considered the new forms unfriendly particularly for children and young people. Some trusts in Wales allowed alternatives to be developed so long as they adhered to the new guidance, whereas, others insisted on adopting the WAG forms. Obviously, there is a contractual obligation for all paediatric physiotherapists as employees to follow Trust policy; however, it is still necessary to be fully conversant with what is expected during the process especially with such complicated forms. The subgroup identified education and training needs on such matters as how to use consent forms appropriately, clarification of issues such as legal requirements, parental responsibility and refusal of treatment. It was felt that training could be cascaded down from within the group over time in addition to any courses staff attended. Therefore, the working party considered that on completion the consent and sharing information project would enhance any Trust/LHB guidance and policy.

Standardisation of consent forms and information

The sub group agreed that where possible consent forms should be standardised. It considered that the existing work in Gwent Healthcare Trust should be the model for a standardised approach to consent for examination and/or treatment by paediatric physiotherapists across Wales. The sub group also agreed that in most instances verbal consent was adequate. However, some treatment modalities and activities were identified to require further risk assessment. Those areas identified were Rebound Therapy, Riding for the Disabled, Electrotherapy, Postural Support, Botulinum toxin, Orthotics/Casting, Respiratory Care, Orthopaedics, Exercise therapy, Water-based activity/hydrotherapy, Mobility – including use of equipment and Video/Photography. It was felt that these treatment modalities and activities would require more detailed information for children, young people and their families in order to gain consent. It was agreed that the development of standardised information, for example, leaflets, videos and CD ROMs on an All Wales basis would be valuable, so the subgroup embarked on the mission of information gathering and sharing. A survey was undertaken across Wales to establish common ground on risk assessment areas and gather information leaflets, videos etc. There was an excellent response from 80% of those surveyed. A gap analysis revealed a variety of information being used for different therapeutic interventions, with not much duplication in terms of information resources available; however, it became evident that many departments had little or no resources. Although the survey was highly success-

Consent - the Welsh Version

ful there were also restrictions to the groups' efforts as they had simultaneously written to Local Health Authorities and Local Health Boards to enquire about their policies on sharing information. Once again, there was a good response rate but it became apparent that these agencies differed in structure, culture and management. Consequently, some were willing to allow sharing of information resources and some were not.

Work in Progress

Currently the subgroup has decided to adopt the Gwent Healthcare Trust consent model as the standardised format for the informed consent process. It is also attempting to reduce the numbers of different consent forms being used across Wales by highlighting the specific therapeutic requirements of paediatric physiotherapists. The subgroup will establish local clinical interest groups to evaluate the information leaflets gathered in the survey and standardise where possible. Then templates will be uploaded to the APCP Wales website and the iCSP Wales web page to increase access for all paediatric physiotherapists. It is hoped that this work will feed into APCP National Executive Committees plans for informed consent guidance for all APCP members.

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Perceived Efficacy and Goal Setting System

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Children's rights to express their views are enshrined in the United Nations Convention on the Rights of the Child and most therapists are willing to listen. The reality is, however, that obtaining the perspective of young children can be very challenging. Parents are a valuable and reliable source of information and, thus, parents are often used as proxies for their children's views (Glascoe 2000). Research indicates that children and adults often have different priorities for intervention (McGavin 1998, Pollock and Stewart 1998). Furthermore, children and young people have clearly stated a desire to be actively involved in decisions regarding their health and its management (Turner 2003).

Enabling children to voice their views requires careful attention to the language used -provision of concrete stimuli such as pictures and clarity of response options. Young children have been shown to access physical competence most accurately.

In order to give valid consent to treatment parents and children should understand what the treatment is and why it is being proposed. When children set their own goals for treatment this is made easier.

Newer methods are required to assist young children in sharing their perspectives of the impact of their disability on daily activities. Careful attention to the language that is used in the questions, the addition of concrete stimuli such as pictures, the clarity of the response options and the context for the assessment can improve the validity of the results. One instrument that uses these techniques and enables young children with disabilities to share their perspectives is the *Perceived Efficacy and Goal Setting System (PEGS)*.

The *PEGS* enables children aged 6-9 years to self report their perceived competence in everyday activities and set goals for intervention. The *PEGS* is based on *All About Me* (Missiuna 1998). It comprises of 24 cards depicting children performing everyday activities. It includes self-care, school and leisure tasks. It has a forced choice format and takes about 20-30 minutes to administer.

The rationale behind the *PEGS* is based on the knowledge that family centred services result in positive outcomes for children and parents/carers. Identifying priorities and desired outcomes for

treatment is a central tenet of family-centred therapy. Explicit and challenging goals can enhance and sustain motivation. Understanding the child's perceived self-efficacy is a necessary part of the process.

A study of 35 children with developmental coordination disorder (DCD) examined children's perceptions of the impact of DCD on activities of daily living using the *PEGS* (Dunford, Missiuna, Street and Sibert, in press). The children were aged 5-10 years, 29 boys and six girls and came from a range of socio-economic backgrounds. All 35 of the children were clearly able to identify whether they thought they were "good" or "not good" at performing the 24 daily tasks depicted on the *PEGS* cards and to indicate whether the child shown was "a lot" or "a little" like them. The children's top goals for therapy were being better at gross motor sports (riding a bike, playing football), independence in self-care activities (dressing, using cutlery) and schoolwork and handwriting. Parent and teacher concerns were collected via a questionnaire with the question "What are your main concerns for this child?" Parents top concerns were about motor skills, schoolwork, handwriting and attention/concentration skills. Teacher's top concerns were about handwriting, motor skills and schoolwork.

Presentation of a couple of case histories follows to demonstrate the use of the *PEGS*. Mark is an eight-year boy who was referred to physiotherapy and occupational therapy by the educational psychologist because of concerns about his coordination. Assessment with the Movement Assessment Battery for Children (Henderson and Sugden) found that his total impairment score placed him below the first percentile. His goals selected using the *PEGS* were:

- Tying shoelaces "cos I can't do them"
- Writing neatly "it goes all over the place"
- Skipping "everyone else can do it"
- Riding a bike "so I can go on bike not scooter"

Rachel is a 10? year-old girl referred to physiotherapy and occupational therapy by the school health nurse because of concerns about her coordination. She scored below the first percentile on the Movement Assessment Battery for Children. Using the *PEGS* she identified her goals for therapy as:

- Being frustrated by her stammer
- Scissors "I like cutting & making things"
- Skipping "I would like to join in with my friends"
- Running "don't want to come last"

Using the *PEGS* has had an impact on service provision in order to be able to treat the goals the children were identifying. Therapy now places a greater emphasis of self-care and leisure activities as well as school based skills such as writing. Links have been developed with the Sports Development Officer and football, rebound and bike skills groups are run jointly with occupational therapists, physiothera-

Perceived Efficacy and Goal Setting System

pists and a sports coach. These groups are run in local leisure centres. The self-care issues are usually most appropriately addressed at home. Therapy has moved out of the children's centre into more appropriate environments. The *PEGS* has also led to a different therapeutic relationship with the children as the starting point is to ask them what they want from therapy and then to work on their goals. This lets the children know that the therapist is listening to them. Once children's goals have been met then discharge is easy, even if the impairment has not changed, the impact of the impairment has been reduced.

In conclusion, collaborative goal setting needs to involve all participants including the child. Children with DCD share concerns about physical/motor skills, academic activities and pencil skills with their parents and teachers. However, the children have additional concerns about self-care and leisure activities. The *PEGS* is a suitable tool to enable children to express their views and set goals for therapy.

Choice - Theory and Practical Application

Jenny Carroll MA MCSP
Bobath Children's Therapy Centre Wales

Choice is the ability to "make a selection" or "to have or demonstrate a preference", or "to be able to decide between possibilities" and it is about "having a right", "the right to choose" (Concise Oxford Dictionary).

In everyday life people make hundreds of choices, whether and when to get up, what to wear, what to have for breakfast, when, where, with whom to eat it, which bowl to put their cereal in, how much milk to have in their tea, the list goes on and on.

For some children with cerebral palsy however, even such basic choices may not be possible. Some children are not able to decide not to have breakfast in the morning perhaps, for example, if they were feeling unwell or not hungry or they may not be able to choose to stop eating because they are full up.

Choice is of fundamental importance to us as humans and how choice is managed is one of humanities defining characteristics. Much of modern legislation (Children Act 1989 and 2004, Human Rights Act 1998,) encourages therapists to enable children to have choice both in their therapy and their lives. The legislation gives children the right to make choices however, how many children with disabilities are equipped to take advantage of these rights? Do physiotherapists have a responsibility to enable children to make choices (within their personal limits)? Should enabling choice, in fact, be one of paediatric physiotherapists' major responsibilities?

This paper reviews the role of choice in therapy and conversely the role of therapy in choice.

Why are choices so important?

Choices are a vital part of development. Typically children begin to make choices very early in life and their ability to begin making their own choices is fundamental to becoming an independent being and part of the separation process from their mother. Children can choose to run away, or to throw a toy from their high chair, thus facilitating learning about space and their environment. They can choose to eat their lunch, or not, which bits to eat first, what to leave. This ability develops with an understanding of possibilities and alternatives and of short and longer term consequence of choices.

For many children with cerebral palsy making those early choices and the initial separation presents numerous difficulties and impairment of their choice making capacity can begin very early in life. It is perhaps useful to look at all the elements involved in choice making in order to consider the complexity and challenges faced.

The factors and processes involved in choice making are highly complex and interlinked. Choices are based on knowledge and experience, which is accessed via our memory. The ability to reframe a concept is important (Bandler and Grindler 1979 and 1982 Sandidge and Ward 1999) and therefore to be able to consider other possibilities; this requires advanced perceptual skills and abstract thought. Cognitive skills are used to help us process choices and speech to convey them or to explore options. An advanced understanding of concepts of time is also important in understanding how choices made may impact on the future. These are high level skills which are, in turn, supported by other skills.

These skills, including to be able to attend, the language to understand options and choices and a sensory system processing information competently are important if the higher level skills are to be attained.

These are again supported by other systems and abilities as shown in this model, (fig 1)

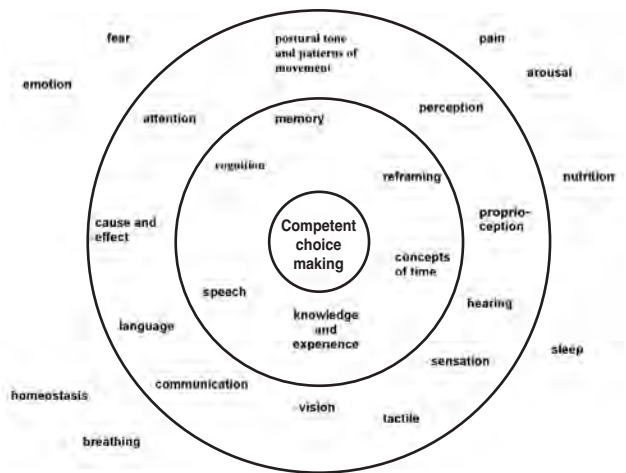


Figure 1

It can be seen from looking briefly at the model that the ability to be a competent choice maker is dependent on a huge number of factors.

For example, pain may increase arousal levels, pain and increased arousal may increase postural tone and lead to abnormal patterns of movement. These factors together, will limit attention and alter perception. This will have an effect on cognition, knowledge and experience and the ability to reframe, therefore compromising choice making skills.

Choice - Theory and Practical Application

If one examines the relationships of these factors to each other, the picture becomes increasingly complex, (fig 2).

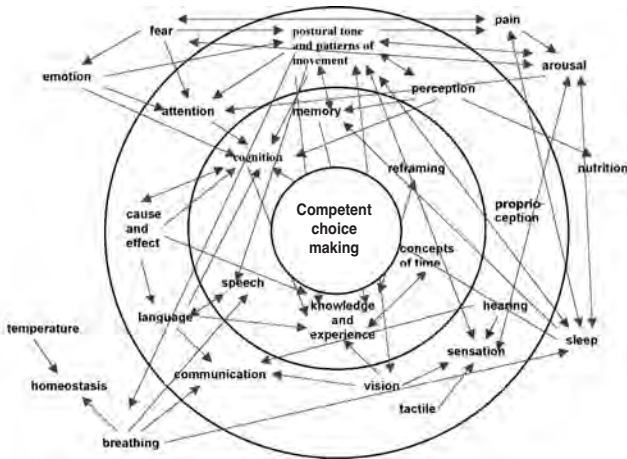


Figure 2

It is the role of paediatric physiotherapists to look at how these factors are influencing an individual child's ability to make choices. When assessing the choice making skills of an individual child, the skills and states on the outer aspects of the model should be reviewed first as these will have the greatest influence, and until they are addressed progress will be difficult. This should be followed by considering skills and states on successive layers moving inwards to each circle, considering the relevant relationships and where therapy may have the most significant impact on competent choice making.

Having difficulties in some of these areas will not necessarily prevent choice making, but difficulties in any areas will impair it to some degree.

For example a child experiencing fear will not be able to attend to a choice being offered, and will be in a state of "flight or fight" with all resources organised to focus on the fear or it's source. There is no point in asking a child sitting on a bench to dress, who is frightened of falling off, what colour socks he would like to wear and expect him to give it any real consideration. His attention will be directed to not falling off the bench. Theories around attention indicate that attention is limited and that "we can think only one thought at a time. In terms of motor behaviour we seem strongly limited in the number of things we can do at a given time, as if some capacity would be exceeded if too much activity were attempted" (Schmidt and Lee 1). A further example "Without language to describe a concept, that concept will not exist for a child" (Rand 1967) immediately limiting their ability to consider that concept in making a choice. If a child has language at a level where all motor vehicles are cars, he will not be able to choose between a police car and a pick

up truck because those things are not different entities for him.

Some clinical examples help illustrate these issues: Siân is a 16 month old girl with a classification of dystonic quadriplegia. Siân has severe fluctuations of tone into a predominant pattern of extension. This extreme posture leads to effortful, noisy breathing with obvious respiratory distress, (a tracheal tug and sternal recession). Siân is in some discomfort. This pattern influences her vision as her eyes are pulled upwards limiting her visual field. When drinking from her bottle Siân lacks sufficient control to pause for a rest or assume a safer swallowing posture. These factors have led to Siân being in a heightened state of arousal.

Siân's main concern will be these challenges and basic life supporting skills. She will have no resources available to attempt communication or to attend to anything else, visually or cognitively. Figure three shows the main (but not only) areas challenging Siân and her ability to participate in choices. These are from the outer edges of our model

Can therapy influence some of these factors that are interfering with her possibility to communicate? Without the groundwork in these identified areas, Siân will not experience communication or choice on any level.

Through handling and influencing her postural tone, patterns and alignment, with tone influencing patterns and graded sensory input, Siân was given the opportunity of moving in a different way and experiencing different movement possibilities. This led to less effortful breathing and potentially improved oxygenation, helping reduce her distress and therefore her hyper aroused state and Siân was then calmer. She now has the opportunity to look, and for limited attention.

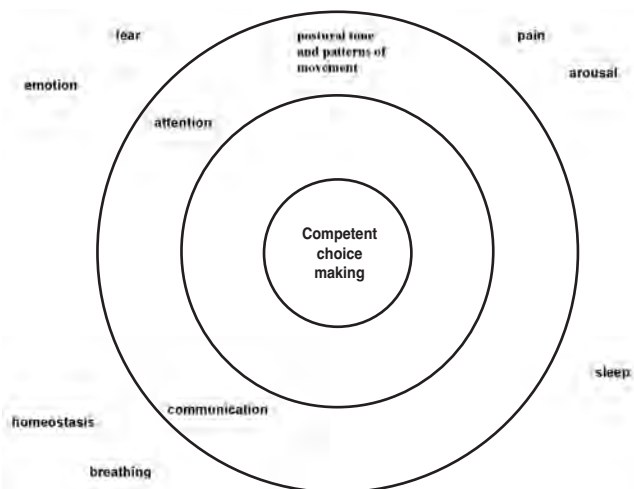


Figure 3

Choice - Theory and Practical Application

Siân needed to be given time to adapt and respond to these changes and the speed of handling and presentation of change needs to reflect this, especially changes affecting her breathing pattern which was quieter and less laboured at the end of her therapy session.

In conclusion a main goal for Siân might be to find a position where she could be calm and attentive on her own or in equipment. This will allow her to extend her choice and would be the foundations on which to build choice making skills.

Janet is a 16 year old young lady with spastic quadriplegic cerebral palsy; she has no verbal skills and a substantial central visual impairment. Her parents interpret her choices for her and she is able to affirm these by smiling. How can these skills be developed and expanded within therapy allowing her parents and carers to see the possibilities, so they can transfer and adapt these to everyday life? In the context of our model, Janet has more of the skills around the outside than Sian, she is calmer and more able to attend, Janet attends auditorily but less visually. The most relevant challenges in the model for Janet are shown below, (fig 4)

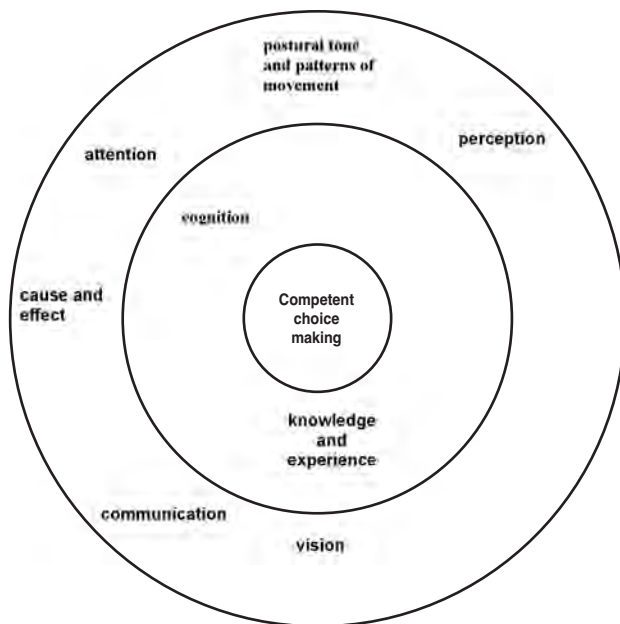


Figure 4

Janet's ability to attend visually is influenced by her postural tone and patterns. Janet's understanding of how she can influence her environment with her actions remains limited and her experience of actively participating in choices is also limited. Her only consistent attempts to communicate are through smiling or pushing into a pattern of extension.

Being able to use her vision to eye point would expand Janet's opportunities to make decisions and indicate choice. Janet's understanding of concepts is at a concrete level and being able to visually perceive and relate to objects would provide a good tool with which to work on communication and choices. This experience would also develop her understanding of cause and effect and alter her level of independence from her parents and immediate carers, removing the need for them to interpret.

What can be done to make this easier for Janet? Improving alignment is obviously an important factor, and was seen in therapy sessions in how quickly Janet is able to use her eyes once her head was supported. Also important is where objects were presented and how we can support her functional vision. Janet is more attentive to a moving stimulus and movement can be used to enable Janet to visually locate objects.

Therapists need to position themselves where it is easiest for Janet to see them and present the objects in Janet's lower left visual field, where her functional vision is best. Janet also needs plenty of time to respond and make her choice, which should be confirmed and verbally reflected back, so Janet knows she has been understood and that she has made a choice. Giving sufficient time for choice making is a vital element for our children.

Hick's law states that response time to choice increases with the number of possible alternatives in a linear relationship (Hick 1952) so if a third choice were offered to Janet, she would require a 50% increase in the time allowed. The extra processing time children need as well as time to convert this to a motor response must be considered.

In conclusion limited communication will lead to limited choice, so it is important to address this in therapy.

Tanya is a two year old girl with fluctuating postural tone. Using the model, her areas of particular difficulty, those influencing her ability to make choices, are her postural tone and patterns and her knowledge and experience. Tanya's play and selective hand function were limited by her lack of postural stability. Tanya was keen to play with age appropriate toys but her choice of how to play was limited by her motor control. She did not engage in symbolic or representational play but played with the objects in a more exploratory way using her sensory motor system rather than her cognitive skills. Given more postural control she quickly developed her skills in this area and was keen to choose the activities, which gave her more experience and helped her to learn. Tanya played in this position for quite long periods, almost impervious of the assistance she was receiving through handling. With the effort and concentration on her posture and remaining upright removed, she

Choice - Theory and Practical Application

is free to concentrate on her activity, improving her learning potential.

It has been shown (Schmidt & Lee 1999) that attending to more than one activity (a concept known as capacity interference) lessens the efficacy of a task performance. Thus if Tanya is attending to her posture on a voluntary level she has not the spare capacity to attend to her play to the same degree and this affects the choices she makes. Thus in therapy choices can be made available to her, by improving her postural control and alignment.

Working to improve a child's skills in any of the areas in the model will influence their ability to make choices. For a child to reach their optimum potential this choice making must begin as early as possible, even six months of age, when choice making is established in normal development, vitally before children learn that they are not able to influence the world around them.

Having looked at how therapy can influence choice it is important to consider the converse of how choice can influence therapy and a child's future functional skills.

As well as the factors in our model affecting competent choice making, competent choice making can also influence the factors in our model, (fig 5).

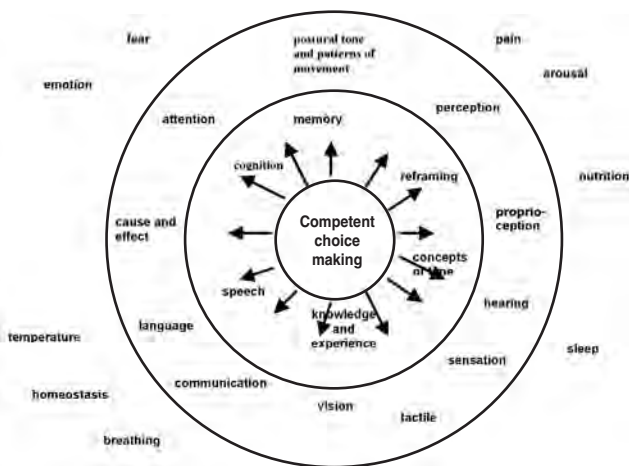


Figure 5

To provide some clinical examples:

Darren has a right acquired hemi athetosis and would choose to use his left arm in isolation for all functional activities. Our role therefore in therapy is to guide him to make different choices and show him what is possible.

It is harder for Darren to perform a functional task with his right hand, and therefore he does not choose to do so for single handed tasks or even to use his right hand in two handed tasks as a stabilising hand. Instead he tends to use his left hand against his body.

This is not surprising; how many people use their non dominant hand for a complex motor task like writing, or even unlocking a door, when both hands are free. However, for Darren the choice not to use his right arm would lead him to a poorer functional outcome in the longer term and eventually to no choice, as less use leads to increased tone, decreased range of movement, abnormal patterns of posture and movement, a further reduction in functional use and so on, in a downwards spiral.

Our understanding as professionals of the normal course of cerebral palsy across the lifespan (Murphy et al 1995, Stevenson et al 1997) gives us a responsibility to help children and families make the right choice. These types of choices, which can be over such a long time span are particularly challenging for us all.

Therapists therefore have to guide Darren to make different choices and show him what is possible. Using a tone influencing pattern to do this uses similar principles to those recently researched (Gordon A 2004 Naylor C 2004) by the proponents of "forced use". Therapists' skills therefore, are in finding an activity that will motivate and enable success with Darren's affected side. Darren needs movement and use of his right side to maintain his upper limb range of movement and the possibility to improve or maintain his ability to carry out two handed tasks.

Decisions about therapy should include the child whenever possible and enabling this choice, as in the previous example, affects the factors in the model. For example, Becky, aged four, knew exactly what she wanted to be better at. When questioned she wanted to be able to push the doll's pram and to be able to go down the slide sitting up and her therapeutic goals were set around this. It is known from Dr Eva Bowers' work (Bower 1994, Bower 1996), that having goals improves the outcome of treatment and jointly set goals allow maximum motivation of a child working towards a desired goal of their choice.

Becky presented with dystonic cerebral palsy in a quadriplegic distribution and these goals would be a challenge for her. Her success in achieving these goals improved her knowledge and experience and her postural tone and patterns of movement, which were changed in therapy to enable her to achieve these goals. In achieving her goals she also had the opportunity to gain visual and perceptual skills and time concepts and importantly develop her self-esteem and sense of success.

Choice - Theory and Practical Application

A further clinical example where the choices made could affect future function is Ben. Ben was a young man of 10 who had no ideas about functional goals and because he had no insight into his own abilities, he felt he could do everything OK already, or at least as well as he would ever be able. His initial choice therefore was not to participate in therapy. This choice was partly as he did not know what might be possible to achieve, and partly that he was afraid of trying and was unsure what might be expected of him. This choice would limit Ben's potential and his future choices.

Ben's reluctance to try new things, limited his possible movement patterns, limited his knowledge and experience and his independence, not just in the present, but in the future. Not trying them also increased his concern and stress when these challenges were encountered. Ben initially became quite upset when trying a new activity was suggested.

With support and explanation he was able to make a different choice resulting in success of which he was obviously very proud, having removed his own shoes, socks and splints for the first time ever.

Therapists' skills must be used to help children reframe possibilities and ensure they are not limiting their own future choices. For example, Ben was limiting his future ability to get himself ready for bed independently, which limited his choice around bedtimes, to sleep over at a mates, to be independent on a school trip and so on.

The ability to make choices and the choices made are clearly strongly linked to a child's independence. This independence is important at all levels, from the child's ability to be positioned on their own or in equipment and gain some sense of self, to being able to communicate needs to carers, to being able to get yourself food and drink when you are hungry or thirsty and not having to wait for a carer, to ultimately, complete physical and emotional independence.

Choice must be introduced in therapy as early as possible. The model suggested provides a possible framework for thinking about choice and its inter-relationships and preceding skills and facilitates thought about choice.

As stated, choice is a fundamental aspect of our humanity and legislation provides us all, including children, with the right to make choices, but this alone is insufficient. It is therapists' role to facilitate and enable that choice to be as much a reality as possible for children with special needs and we as

physiotherapists have the knowledge and skills to help them maximise their choice making potential.

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Collaborative Practice in the Community

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Senior Paediatric Physiotherapist

Managing a heavy caseload in a busy community department requires good organisational and planning skills and some creative thinking.

Over recent years, increased awareness of the needs of children with Developmental Co-ordination Disorder (DCD) has given rise to large numbers of children being referred for physiotherapy assessment and treatment. (The children who present with predominantly gross motor co-ordination difficulties do particularly well with physiotherapy intervention. However, improvements in other areas have also been reported. For example, improvements with handwriting, self-help skills, attention and concentration, speech and language and self esteem.)

A creative solution was needed in order to meet their needs making the best use of available resources.

In an effort to manage the large numbers of children requiring treatment, a return to group therapy was employed. This meant that groups of 8 to 10 children could be treated for an hour per week for 6 weeks by one or two physiotherapists and a physiotherapy assistant. (Blocks of treatment coincided with school terms and were felt to be as effective as the 8 or 10 week blocks referred to by Michelle Lee and Judith Peters in their research.)

It was felt that treating children with motor co-ordination difficulties in a "Medical" setting could have the effect of placing the child in the "sick child role" and make them more aware of their difficulties.

Children's perceptions and feelings about themselves, their identities and self esteem are largely influenced by how well their bodies move. (Marsh and Shavelson 1985 as cited in Winnick J.P. 2000 Adapted Physical Education and Sport.) It can also make the parents/carers less confident about helping their children themselves as they perceive that what we are doing is something mystical.

Working with groups of children being physically active also required a move from the physiotherapy department into local Leisure Centres. This led to children experiencing success in a place where they might not normally attend and would be more likely to visit in the future.

The benefits of group physiotherapy are:

1. The children work in a group of peers with similar abilities which helps their success ratios and therefore, their self esteem.
2. Motivation and competition can be experienced within a "safe" environment.
3. Development of social skills with turn taking and learning to be an "intelligent spectator".
4. There are more opportunities to "Catch the child being good". Working with smaller groups of children with similar abilities enables the physiotherapist to recognise desirable behaviour and good skill performance which can then be rewarded with praise. This helps the child learn good practice and internalise positive messages about him/herself. This can help improve self esteem and ultimately, self efficacy.
5. Parents are encouraged to stay during the sessions and in the case of Dance therapy, to join in. This helps them to recognise their own child's abilities and gives an opportunity to encourage use of other Community based leisure facilities away from "Physiotherapy"

The Children's Centre in Cardiff was able to offer 3 different types of group physiotherapy; Recreational therapy, Rebound therapy and Creative dance therapy.

Recreational Therapy uses activities which are linked to the key stages in the National curriculum for PE. e.g. co-ordination, throwing, catching, kicking, striking and dance. The children also learn to work independently and in co-operation with a partner or in a team. The activities are adapted into games for primary school-aged children and games skills and circuit training for young people. The aims of the session are to work towards the child becoming a physically educated person who has competence at a variety of motor skills, is physically fit, values physical activity, can be creative and can appreciate the performance of others and self. (E.g. how to be an intelligent spectator.)

Gaining knowledge of how to analyse and adapt activities and understand the requirements of the curriculum for PE means that physiotherapists can collaborate with school teachers to help integrate or adapt the class activities to allow for successful participation for the patient.

Rebound Therapy is the therapeutic use of the trampoline to challenge balance, Righting reactions, improve postural tone, co-ordination, proprioception, cardio-pulmonary function and to have FUN! The children practice their social skills by turn taking, being responsible for each other's safety on the trampoline and by being "Intelligent spectators" in order to motivate each other. Rebound therapy has also been reported to help

Collaborative Practice in the Community

with the articulation of speech and to assist the development of receptive and expressive language. The easily achievable goals offer "The just right challenge" so stretch the children's abilities without allowing them to fail.

Following the 6 week course, the parents often asked to continue with the treatment as their children had made such good improvements. However, this was not possible unless it was found at review appointment that the child would benefit from further physiotherapy intervention. It became necessary to find somewhere for the children to progress to so links were made with a trampoline coach who was qualified to teach children with special needs. She now runs several sessions a week and grades the activities to enable the children to work towards trampoline awards. This means that the activities fit into "normal family life", meet the requirements of the physiotherapy aims of treatment, consolidate gross motor skills and lead to successes away from the health setting.

Creative dance therapy uses a qualified dance teacher working together with the physiotherapist in a local community dance studio. Discussions are held prior to the start of the sessions about the physical and emotional needs of the group of children and the "Physiotherapy aims of treatment". The teacher then uses her expertise to use movements that provide the children with opportunities to practice perceptuo-motor skills, improve spatial awareness and give possibilities to explore their own movement abilities and limitations of the physical self. Dance is a wonderful medium to encourage expressive movement because there is no wrong or right way to do it. The parents were encouraged to take part wherever possible to give them the opportunity to have a positive, nurturing experience with their child instead of the often negative relationship that can prevail from having a child with special needs.

After the block of treatment sessions, parents were encouraged to enrol their child at the dance centre in order to access the mainstream classes. One boy joined a Break Dancing group (much to his mother's amazement) and the girls joined in with the Disco dancing classes. The children with more pronounced movement difficulties were able to join a special needs class with their siblings invited to accompany them.

The use of normal sports and recreational activities allows the children to consolidate the skills they learn in the physiotherapy groups. It allows them to pursue physical activities away from the "Health" setting and try activities that fit into normal family

life rather than making time for "Therapy". Often the children will do activities and games at a Leisure centre when they would refuse to do exercises or comply with treatments in the department and once introduced, it encourages the families to use local amenities after discharge from Physiotherapy.

Collaboration has already been discussed previously in this article, taking place between physiotherapists and schools, trampoline coaches and community dance centres. It can be useful to source activity provision that meets the needs of the children before they are discharged. This may mean visiting local authority and private facilities. Some education for the leisure centre and coaching staff may be necessary in order for them to gain a greater understanding of the specific needs of the client group or child, any precautionary advice to help improve the success rate of the participation and prevent injury (e.g. from hypermobile joints) and how to adapt physical activity to help facilitate inclusion. Linking in with the local Disability Sports Advisor will also be extremely helpful when looking for suitable mainstream and exclusive disabled activities in the locality.

When using local leisure facilities for group therapy sessions, it is advisable to carry out a **risk assessment** specific to the activity and the venue before you organise the block of treatments. This means that any potential risks are considered and safety factors can be put in place to limit any potential hazards. It is also important to check out the Insurance cover for the venue and for your activity.

In summary, the use of therapy groups can help manage busy case lists and thinking creatively can lead to the experience being more than about physiotherapy. The benefits are financial, practical and for the child, psychological. Working in collaboration with outside agencies can enhance knowledge of an activity and client group and give a wider understanding of special populations to people responsible in the community for offering physical activity for leisure and recreation. It also raises our professional profile.

Children with a disability may have experienced failure in physical activity situations previously and will therefore require careful programme planning to help foster "Affective goals" (self esteem and self efficacy) which will in turn improve their motivation and pursuit of physical activity as a life long pastime. This is something that we may not assess formally during our intervention (although we may be aware of it) however, it can have enormous implications for the child and their treatment outcomes.

There should be no barriers to physical activity for any disability groups. Although this article refers to

Collaborative Practice in the Community

children with DCD, the same steps can be taken for children with other movement and learning difficulties. It just takes time, planning and understanding to work towards sensitive inclusion in the community.

Everyone needs to be physically active for life regardless of age, sex and abilities and as physiotherapists, we can help start children on the path to a healthier, physically active lifestyle when we collaborate with our colleagues in the field of leisure and recreation.

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The Hopes and Choices of Parents

Caroline and Jemma addressed conference to give delegates food for thought from a mother and child's perspective of the services which are on offer to them

- I am Caroline and this is Jemma
- We have been invited to talk to you about the **Choices and Hopes of Parents, and the Hopes of Children.**
- I am mum not only to Jemma but also to four-year old twins, Kirsty and Rory. I am also Head of Press and Public Affairs for Welsh National Opera.
- Jemma is seven. She is an author, a poet, a composer, a librettist and will be the writer of the Novel of the Year 2009 – so she tells me regularly.
- Jemma has a wonderful dad, Perryn, who is so intricately involved in the story I am about to tell you, that I hope he will forgive my first person singular presentation. Jemma and I wouldn't have got this far without his steadfast support, his love and his unfailingly positive attitude about the future.

Jemma and I were both so delighted to be invited to take part in this conference, but I suspect for very different reasons. For me it is a chance to offer you, the vocational professionals, a chance to have a glimpse into the life on the other side of your case list, so that you might feel a little more aware of the pressures on this side of the care equation.

For Jemma, as she put it 'it is my chance to tell the world my story' and this invitation has given her the feeling that at least a small part of that world believes in her.

You see, Jemma has spent almost her entire life not being believed in – even within our family, we had for a very long time no real understanding of what she understood, what she was thinking or what she was capable of achieving.

It has only been since her fifth birthday that the enormity of her intellect, her potential, and her ambition to fulfil that potential, has started to come through. So what agonies of frustration and despair must she have gone through for those first five years? I shudder when I think about it.

Let me give you a potted history:

Jemma was born in London in July 1997 – she suffered birth asphyxia and has athetoid cerebral palsy as a result. By the time she was six months old it was apparent that all was not right with her development, and we were allocated all the appropriate therapists, doctors, play specialists etc to see us through the nightmare ride of understanding and accepting the reality of having a disabled child.

But one thing was clear to us from the very start – Jemma was bright. There was a gleaming shining 'something' in her eyes, a sense of fun and mischief and keen desire to learn. She couldn't talk, but she was clearly desperate to take an active part in her own life, despite the frustrations of the difficulties of communication and the seemingly insurmountable physical hand she had been dealt. That brightness was clear to us, but we spent five years or more trying to get everyone else to believe us.

So, clutching the diagnosis of cerebral palsy, and Jemma at the age of six months, we began our travels into the rather alien world of 'The Therapy Zone' – a rather frightening and confusing maze. But there was one bright light guiding us as we went.

Right at the beginning, Jemma was assigned to a Lambeth Health physiotherapist called Jan Josefsson - a lovely, warm and very knowledgeable physio. As legions of speech therapists and occupational therapists came and went on a regular basis, Jan stayed with us straight and true. In reality (and I think probably to the chagrin of her superiors!) she took on the role of our keyworker and we looked to her for advice far beyond the physio boundaries. She and I went on a voyage of discovery to research communication devices and full body splints, and examining any number of alternative therapies, some of which we tried, and many we didn't!

Our relationship with that physio, Jan, was pivotal in my understanding and development of my life as a parent of a disabled child, quite apart from Jemma's own physical development. Jemma and I both trusted Jan as a very close friend and counsellor.

From the age of one, Jemma was put through an hour of exercises by me and one of a team of wonderful volunteers who each came to help us once a week. The therapy programme was prescribed by the Brainwave team in Bridgewater, Somerset.

Over the next few years, the programme was updated according to her developing abilities, and 'within her own standards' she did develop – her head control became better and she could roll over. But the most important result of the Brainwave

The Hopes and Choices of Parents

programme came from the continual development of the flashcard exercise, which eventually proved to be the gateway which allowed us into Jemma's remarkable intellect.

Every programme started with flashcards, and building on her understanding of letters and then small words, I was able to create a system of columns and rows of letters. Jemma was able to punch on a vertical column and then one letter on the appropriate horizontal row offered to her.

Using this two stage process, Jemma was able to build up very slowly words and sentences – and I mean very slowly – but at last she was able to communicate proactively. So one month before her 5th birthday, Jemma's communication dam burst. This new discovery, Spell-talking as we call it, changed her life overnight.

After the first month or so of rather tentative, almost pidgin English, her intellect really started to show through. At five years, one month, she described herself: **I am enigmatic**' and nine months later she wrote a 250-word short story called *The Runaway Twins*.

When we moved to Wales at the end of 2002 when Jem was five and a half, our new speech therapist, Paul Deare, took one look at our cobbled-together system and suggested that we could speed it up by adding colour to it, and it worked.

As Jemma got faster, her outlook on life became more ambitious. At six years old she told me **'I would like to outperform the world's expectations of a poor disabled soul by writing a history of the world's peoples'**, - as you can see, irony is a major tool in her writing!

By six and a half, she was planning her autobiography. It will be, she told me:

My Story by Jemma Leech

Everyone we know is in it, and the main protagonists are my family. The book will chart the progress of the life of a young girl who is maimed for life in a birth accident, but who triumphs over all her problems to outperform the world's expectations of her by writing a best-seller.

PS It is for everyone who likes The Railway Children.

And that was just before she told me that although she loved me very much, **'sometimes you are the most demanding old cow on the planet'**! So you can imagine that I was getting a bit nervous about this autobiography!

Late last year, she told me that there was no point in

her learning Welsh, because **'my bestseller will only be written in English'**. I am glad to report however to those Welsh speakers here, that she did write a poem in Welsh for this year's Eisteddfod at school!

Jemma's communication took another huge leap last summer when she made it very plain to me through eye-pointing that she wanted to try to use an alphabet toy which was lying around. And to my amazement she discovered, that with a bit of a steadying hand (or what they now call 'facilitation' in technical parlance) she was able to hit letters direct.

This of course has opened up a whole new area of communication for her. Having battled with her poor motor skills over the last few years to try to master switches for computerised communication, Jemma has since the New Year been using a specialised keyboard, called Intellikeys, which with the help of a facilitator, allows her to access the internet, email, a number keypad, as well as the whole alphabet for typing. Plans are also afoot for her to use it for music composition too – she has an opera in her head apparently, and is just desperate to get it out!

And using a basic communication software package to speak what she types, Jemma has even had a live phone conversation with her grandparents in Scotland – alright, it takes several minutes between each line of dialogue, but it is live and it is proactive.

The next step is to try to organise her a proper portable communication device, and an electric wheelchair. At that stage the world can only be her oyster.

Since we moved to Wales in late 2002, Jemma has gone to the most wonderful school – Palmerston Primary in Barry – a centre of excellence in the Vale of Glamorgan for the inclusion of children with physical disabilities. The staff, have been brilliant at getting her settled and trying to develop her abilities further, without making huge issues out of her disabilities.

The therapy team attached to the school have also been wonderful. In particular, we must just mention Jemma's physio Anne Mahingtheralingham and her OT Jenny Jones, who have given Jem (and me!) such care and attention. We value them more than they will ever realise.

Once we moved to Wales, Jemma was put through the standard Educational Psychology tests, and even our understanding of her abilities was blown out the water. At six years old, her intellectual range lay between 13 and 17 years of age, with her numeracy likely to be even further beyond that. Thankfully, the school is taking Jemma's intellect very seriously, currently teaching her literacy at Year 6 level while she remains in Year 3 for everything else. But my husband and I, along with the schoolteachers, and of

The Hopes and Choices of Parents

course Jemma herself, are now faced with some major decisions to make.

How do you educate a child like Jemma whose abilities are at such extremes? One suggestion was that she should move into secondary school this September – aged just eight. Or that we remove her from school entirely and employ (at our own cost of course) a tutor for her.

So what do we do? An article in *The Times* in October gave us a few ideas, but we are open to any others. So answers on a postcard please to Caroline Leech, address: the Rock next to the Hardplace!

So that is Jemma's story – perhaps an unusual one, but the one I can best use as a reference as I move onto the subject in hand in more general terms.

The Choices and Hopes of Parents

There is one major thing to say about Choice as a parent - I have no choice. I didn't sit down to plan my first pregnancy and think, gosh wouldn't it add colour to my life to have a disabled child. None of us did.

Most of us began our lives as mothers and fathers expecting to have to wrestle with no more traumas than Pampers vs Huggies or mashed carrot vs mashed banana. But suddenly that all changes and you find yourself the mother of a severely disabled child.

Suddenly, along with the trauma of coming to terms with that fact, you are also suddenly having to share your baby and your life with the dozens of professionals each wanting to offer a small bit of the help from their own corner. And while every parent knows that they are all trying to help, it can often feel that these professionals each want to take a little bit from you too.

If you can imagine my life – it was already rather full – small baby, full time job and career, house, family, and friends – the usual stuff. But on top of that I had to find time to share my life with Jemma's

- paediatrician,
- neonatologist,
- GP,
- special needs dentist,
- health visitor,
- special needs health visitor,
- physiotherapist,
- speech therapist,
- occupational therapist,
- dietician,
- orthotist,
- ophthalmist,

- orthopaedic surgeon,
- lycra-splint team,
- physical therapy team,
- early years development specialist,
- wheelchair specialist

– I'm sure I have forgotten someone!

That's a lot of people to cram into an already busy life – and those are only the health professionals!

By the time you add in the education people –

- educational psychologist
- head teacher
- class teacher
- learning support assistant
- education officers
- communication assessors
- IT teacher
- mobility officer

And we haven't started on the social workers, housing grants officers and motability people yet!

Do you wonder why my head (and my diary) is permanently spinning!

What makes life so much easier is when the professionals understand your difficulties. For working parents it makes all the difference to be able to arrange to have appointments at the beginning or end of a day, or if they must be during the day ie hospital clinics, to have those appointments well in advance, not to be called in at a few days notice. Or even better to be able to run appointments together, ie Jemma's physio and OT often join together to save me one appointment.

Another invaluable person was the one who, while being a specialist in their own field, was also aware of what was going on in related areas. I got some great ideas and advice from a speech therapist about the education process, and suggestions about schools from our physio.

The pressures upon any parent bringing up any child these days are huge. But the pressures on those of us bringing up a disabled or special needs child is a hundred times more. And the people that make enormous differences to our lives are you – the vocational professionals.

We may not have a choice, but you do. Your Choice has been to work to help and bring out the potential in disabled children – for that you have my respect, and you deserve a hearty vote of thanks – not just from me, but from every child and every parent whose life you make a difference to.

OK, I was being deliberately provocative when I said I have no choices in all this. Of course I do. Every day I am faced with making small choices about Jemma's life, and every so often I am faced with some frighteningly huge choices to make about

The Hopes and Choices of Parents

Jemma's future. That is where you can make a difference to me, and others like me.

Supporting us in our decisions, and sharing with us your knowledge and experience, gives us Choice, and therefore Hope. Showing us you understand our pressures, rejoicing in small triumphs, believing in our knowledge of our own child and helping us work our way through the maze that confronts us, is all it takes to keep us hoping that it is all going to work out fine.

I am sure that it is not always easy for you to stick to your Choice. It must be hard to be the person who is standing between the Health Authority Management, with its constant eye on the bottom line and on keeping to budget, and the anguished parent who is just desperate to see their child have any opportunity to reach its potential, however costly that might be.

I am sure that you have all had experience of parents at the end of their tether. In my case, Jemma's therapists and teachers are now used to my emotional outburst being in the form of floods of tears on a fairly regular basis. But I know there are parents whose outbursts come in the form of anger and even violence. I cannot excuse that of course, but perhaps can offer you a rationale for it. Lovely, warm and friendly people that you are, you are also sometimes the front face of a big institution which says 'No'.

I am a professional, educated, literate and (how shall I put it?) rather assertive person, and yet I have at times felt utterly demoralised and downhearted by my attempts get the best, or at least an adequate, provision in education and healthcare for my child. It feels that there has yet to be a moment when I am not in the middle of a battle for something.

I cannot bear to think of those who have not had:

- a solid education,
- who do not have access to a computer to write the endless letters to the Education or Health Authorities,
- who do not feel they have the confidence or the right to take on people in power or
- who perhaps do not have English as their first language

How on earth do they cope? And how much do their children miss out on as a result?

How many children do you know who are going without something – a piece of equipment or some specialist help – because their parents can't fight hard enough for it?

The lucky ones

I know I am one of the lucky ones – my child may have disabilities, but she also has huge abilities too. And they will lead her undoubtedly to great things, and as she puts it, will let her outperform the world's expectations of this poor disabled soul, I am sure. And as she keeps telling me, Jemma believes that she is one of the lucky ones too. She has one hope for herself and for other disabled children, the hope that they will be believed in. But of course she can tell you about it herself.

We had hoped that her communication device would have been here today so she could address you personally, but time has got away from us. But believe me, the words that follow are all Jemma's:

The Hopes and Choices of Parents

"For competent and caring people like yourselves, a tale such as mine ultimately will move and amaze you, but it will not change the way you deal with your child patient list, will it?"

"A child is not like a toy, now and then to be taken out of the cupboard for a fun half an hour until something more interesting catches your eye. He ought to have the full attention of his team of expert doctors, therapists and teachers, or opportunities for development will just fly by, leaving pain and frustration in its wake.

"Decades ago, a child like me would have been stuck in a home for cripples, and left there to rot, till death gave them a chance to escape the misery. Even coping nowadays with disabilities like mine is no bed of roses.

"Going heavenwards eventually forms a fairly final closure on agony and 'poor soul'-dom, but for those of us for whom the bell does not yet toll, few hopes are more fervently fought for than that of a child who wants to be believed in.

"Being believed in hasn't yet meant that I can expect a certain future where all my abilities are accepted without lots of lobbying from my mum. But it does mean that my parents have had their own hope fulfilled. Belief in their deep understanding of me, and my needs and ambitions, has given them a sense of being empowered to change the world; my world at first, but get her wound up enough and my mum will let nothing get in the way of every disabled child having the same chances as me to reach their true potential.

"But she can't do it alone, you are the ones who fight on the front line every day, and the hopes of children like me lie firmly in your hands. Please look after them - Hope is a very fragile thing."

Need I say more?

Caroline and Jemma Leech

April 2005



Poster Presentation

APCP Conference - Swansea 2005

Questionnaire Survey on Treatment Principles used in the Management of Cerebral Palsy

Bendall AL1 and Pickering DM2

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Introduction

Children with Cerebral Palsy (CP) present commonly with spasticity which provides physiotherapists with the management challenge of maintaining alignment during growth and minimising the long term effects of this sensory/motor disorder (Edwards, 2002). The involvement of the paediatric physiotherapist in linking specialist knowledge to their treatments is paramount and a wide range of treatment principles have evolved to manage CP and the associated spasticity in the UK (Scrutton, 1984).

In the literature there is common agreement that early intervention is the most beneficial and the motivation of the child and family involvement is of paramount importance in determining the outcome (Levitt, 2004; Bower and McLellan, 1994).

There have been periodic calls for the scrutiny of the effect of physiotherapy on children with CP (Bax and MacKeith, 1970; Mead, 1968). There are limited sources of rigorous physiotherapy research that have evaluated treatment effectiveness on children with CP (Bower and McLellan, 1994; Knox and Evans, 2002). The recent Clinical Governance Agenda is driving the need for Evidence Based Practice and so physiotherapists must be able to justify their clinical reasoning on a sound basis (Jones et al, 2000).

The stronger the knowledge base upon which physiotherapists underpin their clinical practice must surely give better value for money and quality assurance (Higgs and Titchen, 2001). There is therefore a real demand to focus on the ways that physiotherapists are acquiring knowledge of treatment principles. Additionally, physiotherapists need the skills to interpret this evidence

Aims

- To identify the treatment principles that are used currently by community paediatric physiotherapists.

- To identify where the knowledge and expertise was learnt for the range of treatment principles used.

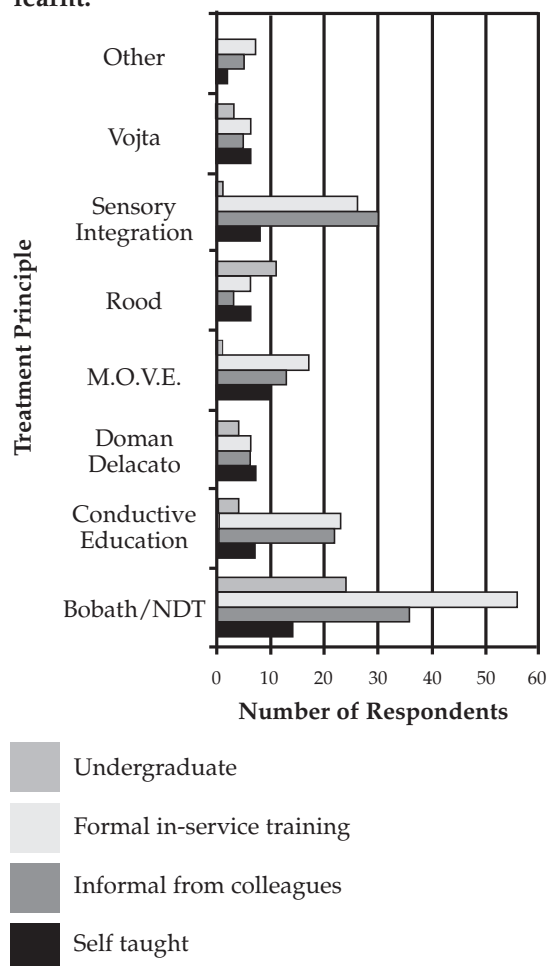
Method

A literature search was conducted for evidence of treatment principles used in the management of CP. Those treatments available are Bobath/Neuro-Developmental Treatment (NDT), Conductive Education (CE), Doman Delacato, Movement Opportunities Via Education (MOVE), Rood, Sensory Integration (SI) and Vojta (Hare et al, 1988; Levitt, 2004). In addition an eclectic approach is described which uses a combination of several different principles (Levitt, 2004).

The School of Healthcare Studies Ethics committee at the University of Wales College of Medicine approved the study.

A questionnaire was designed based on the evidence found of treatment approaches. The questionnaire survey was carried out : 120 questionnaires were sent to eighteen randomly selected children's centres from the Child Development Directory.

Figure 1: Bar chart of where treatment principles learnt.



Poster Presentation

Results

A response rate of 63% was achieved with 76 questionnaires being returned. All respondents were female which is a fair representation of this speciality. The mean time spent working in Paediatrics was 13.3 years with a mean of 18 children on their caseload with the spastic type of CP.

Table 1 shows the 4 most commonly used treatment principles: Bobath/NDT: (96%), SI: (36%), MOVE: (18%) and CE: (18%). In addition 4 treatment principles were reported which were not found in the literature review, namely: Brazelton, Halliwick, Nancy Hilton and Targeted Training. All of the respondents used a combination of principles and demonstrated an 'eclectic approach' to patient management.

The results were analysed by descriptive statistics looking for trends.

Figure 1 shows a bar chart of where the respondents had learnt their treatment principles which demonstrates a predominance for in-service and informal from colleagues. Of the respondents only 28% had attended post-graduate courses. There was a trend for physiotherapists to have read more about a treatment they were not currently using and less about one they used frequently.

Treatment principle	1st choice	2nd choice	3rd choice
Bobath/NDT	72	1	0
CE	0	9	5
Doman Delacato	0	0	0
MOVE	1	8	5
Rood	0	4	0
SI	0	23	4
Vojta	3	0	0
Eclectic	0	2	2
Halliwick	0	1	0
Nancy Hilton	0	0	1
Targeted Training	0	2	1

Table 1 reports the frequencies of treatment principles chosen in order of preference.

Discussion

The results showed that 28% of respondents had not attended any postgraduate courses and many had learnt most of their skills from in-service training or informal from colleagues. Gosling (1997) suggests that postgraduate courses and qualifications have little relevance to patients needs and so the motivation to follow such postgraduate training is minimal.

The study demonstrated that in current practice physiotherapists are using treatment principles which have a **limited evidence base**, and there was evidence that less had actually sought literary information and read about these treatment principles. Furthermore, those respondents who had not attended postgraduate courses would not have the benefit of the present undergraduate courses where students are taught how to retrieve and appraise literature. This could suggest perhaps a **training need** for those who have not been able to learn the skills of information retrieval and critical appraisal (Bardin, 1998).

It was clear that Bobath/NDT and SI were the two most frequently selected treatment principles and the knowledge base for these came primarily from formal/informal training from colleagues. If this is a representative trend, it would suggest that quality of in-service/informal training should be of the highest standard. This on going professional development requires the resources and skill mix to ensure staff competency in the effective management of CP.

Conclusions

There is a need to demonstrate **evidence based practice** in the management of CP in children. This involves physiotherapists updating their knowledge although currently from a limited evidence base.

To give these patients the best, most cost effective treatment more rigorous evidence is needed, but then physiotherapists require the necessary skills

Acknowledgements

The authors would like to gratefully acknowledge the time the respondents gave to participate to provide this data and wish to assure anonymity and confidentiality of the data.

APCP MATTERS

News from National Committee

National Committee met prior to the opening of conference in Swansea with a packed agenda and slightly more pressure on time than usual.

Sally Braithwaite was able to report that the proposed DCD meeting had taken place with Gill Brown attending as a representative from NAPOT. The objectives of the group include producing a working document for DCD which would be relevant throughout the UK and include other disciplines. A mapping exercise will identify current practice with the proposed date for a further meeting being September 05.

There will be a further meeting of the Botulinum toxin group in July with a larger meeting scheduled for the autumn where it is hoped to also gather information about current practice and present the work to date. These meetings will take place in London, dates to be confirmed.

The Neuromuscular interest group inaugural meeting will be held at CSP, London on 27th May and Gill Holmes will represent APCP at this meeting. It is hoped that the Neuromuscular Interest group will become the third A.P.C.P. affiliated group.

Peta Smith and Jeanne Hartley are collaborating with Prabh Sulaman, PRO at CSP to produce and promote a "Tummy Time" leaflet with particular relevance for Plagiocephaly.

The booklet, "Handle me with care, Supporting your premature baby's development" and other leaflets have now been produced and are available direct from Bliss www.bliss.org.uk.

The Outcome Measures Pack, produced in collaboration with PPIMS was available at conference and can be purchased from Lorna Stybelska, A.P.C.P. Publications officer. The committee thanked Adele Leake for her considerable input to this project.

Committee members have been invited to contribute to or comment on a wide range of topics including public health and ethical issues and clinical topics such as the new Paediatric on-call package.

Progress with the re-designed website has been slower than anticipated, however we hope to see some progress before the July committee with a re-launch in October at CSP congress.

Education and Research committee continues to

develop and promote courses Adele Leake has produced an information pack for teachers and a tutor support pack for physiotherapists who agree to teach on APCP courses. She is reviewing procedures for quality assurance of courses run using the APCP name and for validation of courses. Jeanne Hartley is working to support paediatric physiotherapists with an interest in research.

Planning continues for CSP congress in October 2005 and future conferences in Glasgow 2006 and South East Region 2007.

The next National Committee meeting will be on 8th July and your regional representative will be happy to raise any issues on your behalf.

Many Thanks to Wales for their generous hospitality

Laura Wiggins
Secretary

Clinical Interest Group Liaison Committee report

This is a brief report on what is happening in the Clinical Interest Group Liaison Committee (CIGLC). The group now meets three times a year, the last meeting was Wednesday 19th January and the next is 25th May 2005.

'Time off' issues to support CI/OG activity was discussed again and it was highlighted how important it is for CI/OG members to promote their involvement to their managers, especially as the work is beneficial to CPD and the Knowledge and Skills Framework Profile. Different ways to support this included: ensuring the time off required for CI/OG representation was agreed by managers; emphasising the benefits of being a CI/OG member using the CI/OG Information Pack; encouraging supportive managers to write short articles about the benefits of staff being members of CI/OGs for Managers News or similar as well as seeking support from members of the Association of Chartered Physiotherapists in Management.

Involvement of the CSP in response to the 'Public Health in England' agenda was highlighted. A draft policy briefing had been circulated for discussion, consultation and involvement. The final draft of the paper will be circulated to the CSP committees in May 2005 and should include examples of physiotherapy services.

The CIGLC continue to work with the CSP officers to develop: the Society's future Education Role; Interactivecsp; Electronic CPD, Congress 2005 and 2006; ARC; involvement with the DoH and DfES national consultations and the Information Papers to support our practice and professional

APCP Matters

development. Much of this is done through consultation with members of the committee (and then to their own committees), short life working parties or electronic and teleconferencing communications. The minutes of the CIGLC meetings and all draft Information Papers are circulated to your national committee and regional representatives so please feel free to contact them for detailed information or if you wish to take part in any of the consultations.

On a more general note, the CSP continue to support the CI/OGs in many ways, not least through the capitation awards, the training for the CI/OGs Officers and the work involved in maintaining communication to ensure active involvement and consultation.

For any further information or any queries please do not hesitate to contact me on 01268 886237 or email linda.fisher2@essexcc.gov.uk or tnandlgfisher@aol.com.

Linda Fisher
Clinical Interest Group Liaison Officer

RESEARCH AND EDUCATION

RESEARCH

Early spring has been extremely busy for me but one of the highlights had to be the APCP Conference in Wales. What a stimulating event- so good that I changed much of a talk on CP I was giving at a conference in Majorca four days later to include some of the fascinating insights into listening to children and their families about what is important for them. Never one to have things ready until the absolute last minute changing what I wanted to say was not a problem and the talk was all the better for me having been to Wales! It was very nice to meet some of the people who have been in touch since I became research officer too – at last I can put faces to your names.

Research Group Meeting: April 18th 2005.

Our little group is slowly expanding and hopefully will continue to, as an increase of 25 % in attendees at the last meeting was very welcome! This number may not be highly significant statistically due to the small population but a fourth person to join the usual three was highly significant for us! Other people have been in contact about the group but the day was not convenient so we have changed the day of the next meeting in the hope that more of you will consider joining us.

The next meeting will be on Thursday June 30th at Great Ormond Street Hospital from 2-4pm. The topic will be critical appraisal of a Journal article and will be led by Lucy Alderson who is studying for a PhD. If you would like to come please could you let me know – mainly so that I can send you the article we are going to look at – but also so I can let you know where in Great Ormond Street we will be!

Just in case you can't make it the next meeting will be on Thursday 22nd September at Queen Mary's Hospital in Roehampton when we hope to discuss: How can you do research as a full time clinician with no spare time? Should make for an interesting discussion!

These meetings do not have to be London based – they are only in London because that is where the group is – so far. If you would like to join us but can't travel a long distance how about finding out if there are like-minded people in your own area

One of the things we did talk about at the last meeting was how useful some of the parent groups are for accessing information about conditions, data gathering, long term prognosis, outcomes etc. From my own perspective I am a big fan of TAG (The Arthrogryposis Group) and attended their conference last year as a speaker. However the big thing for me was meeting young people and adults

with arthrogryposis and listening to their opinions about health provision, (particularly physiotherapy!), as well as finding out about their achievements and problems. Many of these condition specific groups hold conferences every year. We thought it might be useful to let you know when some of these meetings are just in case any of you are thinking of carrying out studies of the qualitative nature or looking at outcomes you might find some rich information available to you should you attend. If you know of any conferences coming up please let me know.

So to get you started:

The Jennifer Trust Conference September 10th 2005 at Whipsnade Zoo, Bedfordshire.

There will be a full programme of presentations on the latest drug trials, genetic studies etc regarding Spinal Muscular Atrophy. www.jtsma.org.uk

TAG annual Conference (The Arthrogryposis Group) 23rd –25th September 2005 in Manchester. www.tagonline.org.uk

FUNDING OPPORTUNITIES:

As you may guess, a lot of the information I get about research funding gives very short notice for applications or arrives just as the copy date for the next Journal has passed - by the time you get the next Journal there are a couple of weeks left to get applications in. If any of you are looking for funding for projects do give me a call – you may strike lucky! If any of you should have information about funding please do consider sharing the information via these pages.

Health Foundation: Leading Practice Through Research

The final round of this award scheme has just opened.

This award enables mid-career professionals, from a wide range of backgrounds in the health sector, to undertake research as a means of enhancing ability to make a direct difference to the quality of patient care or the health of the population in the UK.

A broad range of quantitative and qualitative research activities will be considered eligible for support. The Health Foundation is particularly interested in receiving requests from applicants wishing to upon a professional career through the development of leadership skills, which may include aspects of management training (i.e. influencing and negotiating skills), team building or specific leadership training.

The award may be held for a minimum of 6 months and a maximum of 2 years (full or part-time). Healthcare practitioners,, health improvement practitioners (including public health professionals) and health service managers and policy-makers are eligible to apply.

Research and Education

Deadline for the receipt of applications is 4th August 2005

This needs to be accessed via
http://www.grantfinder.co.uk/profile.php?p=downloads&newsflash=UN3910_UE6890_Health_Foundation.doc

Commonwealth Fund 2006-07 Harkness Fellowships.

Anyone interested in spending 12 months in the USA conducting a health policy oriented research study should look at Alex Warne's posting on the ICSP website. Information about the programme, eligibility and selection criteria, a list of suggested projects and the application process can be found at the Commonwealth Fund website. **The deadline for receipt of applications is September 1st 2005.**

Sorry for the short notice of this one (again from iCSP) – but this may be the one for youoooo!

The Nancie Finnie Charitable Trust research fund

Applications are invited from suitably qualified therapists wishing to undertake research in the area of rehabilitation of the child with CP. Multidisciplinary projects are encouraged. The Trust is small providing for an annual distribution of funds in the range of £25,000 - £30,000.

Application form and guidelines from the Trust's principal office: 18 Nassau Road, Barnes, London SW13 9QE, enclosing a large S.A.E.

Applications no later than **30th June 2005.**

Well that's all for now. Please do contact me if you would like to have a chat about your research projects or ideas or even think of joining our group for peer support!

Jeanne Hartley
Research Officer

EDUCATION

Recent courses.

There have been two recent APCP courses held "Introduction to Paediatrics" in Belfast and "Advanced course on Cerebral Palsy" in Derby, both courses were very well evaluated and the course participants found the courses informative and valuable.

Quality Assurance Pilot Scheme.

The education committee is undertaking a pilot scheme to evaluate a quality assurance mechanism for APCP courses. The aim of the QA scheme is to ensure that all APCP courses are of the same high quality. This will enable our members and their funding bodies to have confidence in the standard of courses approved by the APCP. We aim to have the pilot scheme up and running in the next few months and will ask some course organisers to participate in the scheme. The results of the pilot will be available for congress in October to help to inform the next years planning for the education committee.

Congress 2005 – 7th October

Don't forget to look out for the congress programme on the CSP web site, we have tried to ensure that the programme is applicable to many members.

- Chronic fatigue syndrome can be a very challenging part of our case load, both in the acute and community setting, often leaving physiotherapists feeling frustrated and lacking appropriate skills. Robyn Hudson will present information based upon an international perspective of working with children with Chronic Fatigue syndrome.
- Pilates has been gaining great impetus in both the recreational and therapeutic exercise fields. Despite this, very few Physiotherapists have been successfully using Pilates with Children as the transition from an adult to a child friendly approach takes creativity and innovation. Maryanne Horton has been using Pilates with children for many years and will share her insight and experience, to help explain how Pilates might be appropriately applied within paediatric practice.

It should be a very interesting day. Put the date in your diaries!

Call for new teachers

Thanks to the few people who volunteered their services to teach on APCP courses in the future, we now have an expanding database of people to call on. We still need more of you to help. I'm sure many more of you regularly teach undergraduate students and induct new members of staff into your workplace and you would be ideal teachers for our "Introduction to paediatrics" courses which run all over the UK. If you are interested we will offer you support and payment for your teaching, you will be offered dates, times and places which you can accept or decline as suits you. You are not bound to teach for us if you just express an interest. If you are interested, please write to me or drop me an email.

Adele Leake
Education Liaison Officer

**THE
2005**



***for innovation in
paediatric
physiotherapy***

The award worth £1,500 is open to ALL UK paediatric physiotherapists who may enter on an individual or group basis.

It is designed to help therapists pursue areas of innovation both within the sphere of their own work and that of the profession as a whole.

Sponsored by Jenx Limited, the UK's leading manufacturer of equipment for children

Award to be presented at the APCP Day at Congress in October.

REGIONAL AND SUB-GROUP REPORTS

SOUTH WEST

Firstly many thanks to Ruth Davies who has served as chairperson for the last 4 years and to Clare Olsen who has been our regions treasurer, both of who will stand down at the next regional AGM. They have both performed sterling jobs during their time as part of the south west regional committee and we wish them both well. This will leave vacancies on the regional committee and we will shortly be looking for willing recruits to fill these posts and committee member vacancies.

A hydrotherapy course, an introduction to the Halliwick concept is due to be held in Southampton in May (still to take place at the time of going to press, but under Clare's supervision, no doubt a huge success). A PE course is still planned for the Dorchester area, due to difficulties finding a suitable venue in the area a firm date is yet to be announced. A sensory integration course is being planned in Salisbury in the summer. Watch out for future flyers.

Here's hoping for a warm dry summer this year.

LYNDA NEW

SCOTLAND

We are delighted that Dr Terry Poutney has agreed to lead our Study Day on Friday 17th June 2005 under the title of postural management. Terry's presentations will give a comprehensive view of postural management from assessment using the Chailey levels of functional ability, through the bio-mechanical approach to the prescription of postural equipment and the evidence base for changing management of the hip.

Our Regional Annual General Meeting will be held just before lunch. Over lunch there will also be time to network and also look over the equipment exhibition.

Our Study Day is being held for the first time in the Craighalbert Centre in Cumbernauld. We hope this central location will enable as many members as possible from across the country, to attend.

Plans for APCP Conference 2006 are well underway. The conference accommodation at The Moat house Hotel in Glasgow is booked and we are structuring our programme around the title, **Living and Learning—Challenging Expectations**. The Neonatal and Critical Care SIG Groups will also be involved in the programme planning. Although planning is at an early stage, we hope to provide a programme, which will be of interest to as wide a spectrum of paediatric physiotherapists as possible.

ALISON GILMOUR

NORTH EAST

The study day in April on 'Postural Management' with Terry Pountney was a resounding success. The day was oversubscribed and it was great to see so many members at the AGM. Terry's presentation will have given delegates renewed ammunition to seek essential funding for postural management equipment.

Our next study day, 'Multi-disciplinary Approach to the Management of DCD', will be held in the Postgraduate Centre of Goole District Hospital on Wednesday 9th November 2005. There will be three speakers:- Heather Angilley PT, Sarah Stanley OT and Bron Canwell, Specialist Teacher. Further details for the day will be sent out on a flyer at a later date to NE members and will also be in 'events' on ICSP Paeds Network.

On behalf of our local committee, I would like to thank two of our retiring members for their hard work and commitment. They have both held very responsible posts, giving of their free time without question for the benefit of the NE region and are going to be greatly missed. Jayne Hallford has completed her eight years on the committee and has been the Treasurer for the latter years. Jan Kelly has resigned from her post as Course Co-ordinator. However, we look forward to meeting new members at our next committee meeting towards the end of June. Should anyone consider joining the committee at this stage it is not too late - you can be co-opted on.

Finally, congratulations to Wales for hosting an excellent annual conference in Swansea.

MARY HARRISON

LONDON

It is the most beautiful sunny day and as I write this it reminds me of the last day of conference in Swansea which was equally gorgeous. I and many others couldn't resist a walk down the beach before heading home. What a fantastic setting for an excellent few days. London regional committee all wish to say a big thank you to the organisers for a stimulating and highly relevant programme and great entertainment. We were rather disappointed no one from the region responded to the offer of a free place. Next time go for it you never know - it could be you!

Continuing with conference we were delighted to see the team from St Mary's Paddington with 2 superb poster presentations. We extend our congratulations to Rebecca Biggs who won the competition with an exceptional piece of work which was highly acclaimed by the judges. It is great to know there is such a lot of talent out there.

Talents continue with some excellent collaborative work coordinated by Charlton Park School, Greenwich, looking into all aspects of equipment use in paediatrics which was reported on in the last

Regional and Sub-Group Reports

journal. The 'Standing network' sound an exciting project which will pool current research and experience to offer real benefit to us clinicians using equipment.

I am very pleased to report all committee places are now filled with 3 new additions. Thank you for coming forward we now have a great mix of grades, and also representation from the private sector. We are currently working on the new programme of lectures which will be advertised as usual by flyer and email. The committee send congratulations to Vathana who is getting married in May, we excuse you from the AGM! We also send very best wishes for a speedy recovery to our treasurer Sarah Prior who has been unwell.

If you don't get information at your London workplace (you may belong to another region because of your home address) let Christina have your work address. If you have any news to share, research projects, team developments etc drop Christina or me a line so we can add them to the information we circulate. Have a great summer.

STEPHANIE CAWKER

SOUTH EAST

Once again – greetings from the South East.

Since my last report I have attended the APCP Conference in Wales. This was the last Spring conference as, from now on, Conference will be in the Autumn. APCP joins CSP Congress in Birmingham on 7th October this year - you might want to think about joining us for the day?

There were some excellent speakers at Conference in Wales (you should have been there!) and we were blessed with spring sunshine. The energetic among us went for long walks/runs along the beach of Swansea Bay and the less energetic explored the delights of the Mumbles. As always the opportunity to network with paediatric physiotherapists from other parts of the country was a real bonus and the exchange of ideas very stimulating - I took part in a very lively workshop on Consent!

Closer to home we have just about completed arrangements for the Study Evening and AGM on 15th September 2005 at Bluewater near Dartford. As you may remember from this column, and the Questionnaire which we organised last year, we are very keen to encourage attendance at this year's meeting - so look out for the flyers, application forms and the "Special Offer".

Finally, although 2007 seems a long way off, the time for us to organise APCP Conference in the South East is rushing towards us. Finding a venue is the first challenge, so - if any of you have used/know of a venue with excellent conference facilities, superb

accommodation and easy road, rail and flight links please get in touch with me asap. My contacts details are at the back of the Journal.

Have a good summer.

ANN MARTIN

WALES

My most important news is of course – Conference, held in Swansea at the end of March. Having occupied most of our lives for about eighteen months, the moment came and, I think for most people on the organising committee, passed in a haze of worry, apprehension, fear and then giggling relief when we realised that all was well and the Conference was a success. All of those who were delegates were impressed by the standard of speaker and the variety of subjects on which they spoke whilst still adhering to the main theme of "children's voices, parent's choices". The evaluation forms certainly confirmed this impression, as did your many cards and phone calls in the week following.

Roy Noble was a star turn at the Conference dinner, as were the Morrison Orpheus Choir and Y Mabon. Delegates were impressed, if not stunned into an appreciative silence for the choir and much praise for Mr Noble came from everywhere.

All in all, an excellent three days of information, communication and education; and, on the last day, the sun came out!

Copies of speakers' presentations are available in this edition and in subsequent Journals, plus photographs of the events.

JILL WILLIAMS

NORTHERN IRELAND

Since the last journal we have had our A.G.M. It was good to see those of you who were able to make it that evening. However it is disappointing that so many of our members do not make these evening meetings.

Following our AGM we had a most interesting and informative talk by Deirdre Martin on Baby Massage. Deirdre raised our awareness to a treatment modality, which few of us know much about. The discussion continued over wine and cheese!

Felicity attended the national conference in Swansea. We look forward to her feedback on the event some time later this year

Gemma Lipscomb has taken on the role as APCP rep on the N.I. C.S.P board. We are grateful to her and feel it is important to have a paediatric voice on this committee

Hopefully you have all been making use of interactive CSP. The new interactive APCP site should be going live soon. Sheila McNeill has agreed

Regional and Sub-Group Reports

to take on a local moderator role for the site in the initial period (so if you've any queries please see her!)

As a committee we hope to meet in the next few weeks to plan next year's events. There is still a lot of discussion as to when it would be best to hold our meetings to facilitate best attendances. Some of our committee want to retire from office, however we are having trouble recruiting replacements. If you feel this is something you could do please do not hesitate to contact us

Looking at our membership we could do with recruiting some new members. Can we encourage you to promote APCP particularly with new and/or younger colleagues? We would especially look forward to any ideas they may have for us on committee!

Hopefully we will be in touch with you towards the end of the summer with details of next year's events.

ALISON MOUNSTEPHEN

NEONATAL SPECIAL INTEREST GROUP

(Affiliated to the APCP)

BLISS BOOKLET

At last, the long awaited BLISS booklet is finished and available for ordering. To get your copies of "Handle me with care – supporting your premature baby's development" go on line at www.bliss.org.uk or phone 08712448506, as professionals you will need to pay P&P. Parents can order on line as well or by phone on 02078209471 and they receive their copies free of charge.

This booklet is one of a series of publications supporting the preterm baby. It is recommended to be read together with another booklet called "Look at me – I'm talking to you", which is a direct translation from a French booklet called "Je vous parle, regardez moi" and is produced by SPARADRA and sponsored by the Pampers Institute. This booklet deals with the emotional needs of the preterm and enables parents to understand what the baby is saying to them. The content is based on research by Dr Heidelise Als.

We hope you find them helpful and ask that you encourage lots of feedback, and direct it to BLISS and Peta Smith so that all comments can be taken on board.

COMPETENCIES

A selection of the committee met in December at Nottingham to review those competencies most relevant to Physiotherapists working in the field of Neonates. A tabletop discussion proved very useful and we were able to send feedback on these for "Skills for Health" to consider. There will be more work on this in the future.

AGM & STUDY DAY

This is scheduled to be in Bristol on Wednesday the 19th October. Details will be posted on the icsp web site.

ADVANCE NOTICE FOR 2006 APCP CONFERENCE

We plan to hold a Satellite Neonatal Conference at the APCP Conference in 2006 in Glasgow, 10 – 12 November. The theme will be "Nature and Nurture" and this will offer delegates the opportunity to attend lectures from the Neonatal Conference as well. This is a really exciting opportunity and we hope to have as fantastic an experience as we did in Edinburgh.

MEMBERSHIP

Can I please remind everyone that you should have renewed your membership at the beginning of the year. You are required to do so on an annual basis and if you do not, then you will not be on the database and will also not receive a copy of this. For details contact Nicky McNarry on member @mcnarry.freemove.co.uk

Congratulations to our secretary Nicky McNarry and her husband on the arrival of Max, we wish you all the best and hope you enjoy your time off to 'play, and practise'.

BARBARA HAEDERLE

APPLICATION FORM FOR A.P.C.P. PUBLICATIONS

Dated June 2004

2005	
Paediatric Outcome Measurement	£20.00
2003	
Special Educational Needs	
Code of Practice 2001	
Guidance for Paediatric Physiotherapists	£10.00
2002	
Paediatric Physiotherapy Guidance for Good Practice	£5.00
Obstetric Brachial Plexus Palsy	
A guide to physiotherapy management	£10.00
Hip Dislocation in Children with Cerebral Palsy	
A guide to physiotherapy management	£7.50
Evidence Based Practice	
• Management of Obstetric Brachial Plexus Palsy	£3.00
• Hip Subluxation and Dislocation in Children with Cerebral Palsy	£3.00
OR	£5.00 for the pair
Paediatric Manual Handling – Guidelines for Paediatric Physiotherapists	£10.00
Human Postural Reactions – Lessons from Purdon Martin by Dr J Foley	£5.00
Baby Massage	£1.50
The Children Act 1989 “A synopsis for Physiotherapists”	£1.00

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BOOK REVIEW

Handle me with care – Supporting your premature baby's development.

Look at me – I'm talking to you! Watching and understanding your premature baby

Even though I had never reviewed a book in my life...and I apologise in advance if I haven't done it properly!...I was delighted to be asked if I could review these newly published booklets by BLISS which were produced in collaboration with the APCP Neonatal Group. Mainly because as a physiotherapist working on a Neonatal Unit, they are just what I wanted!

On first impressions, these booklets look very professional but friendly and personal at the same time, with eye-catching titles. From the outset, both are very clear about their contents and their aims in meeting the needs of a premature baby.

The **Handle me with care** booklet provides information on the preterm baby's physical needs and development through supportive positioning and handling whilst on the neonatal unit and at home. It states quite clearly that every baby is different and the importance of parents and staff working together. It also includes the appropriate safety notes. The text is quite detailed hence the 37 page booklet but it is very well presented and easy to read. It is supported by fabulous real life pictures (my favourite bits!). I also like the section which helps parents to recognise their baby's signals and body language which is reinforced in the **Look at me** booklet. The "at home" section is very useful with advice on sleeping and playtime positions as well as information on supported sitting. The text is well supported by references.

The **Look at me** booklet covers a preterm baby's emotional needs and helps parents to understand their baby's body language and behaviours. It encourages parents to provide the appropriate physical and social environment in which their baby can grow and develop, giving them a positive role whilst their baby is on the neonatal unit. Again, this booklet is well presented with some nice illustrations.

These two booklets complement each other beautifully!

I thought it would be a good idea to ask a few other people what they thought and this is what they had to say:

"Wonderful booklets, nice and clear, just simply helped me to understand my little girl's behaviours and how I could help to provide a better environment for her to develop" (Parent)

"Lovely to have professional looking written reinforcement to complement the information given to parents on the unit and at home. Demonstrates the importance of parents being involved with their baby's development so giving them a definite role. Very useful teaching tools also!"

(Sarah Davies, Senior II Physiotherapist and Bethan Sheen,
Junior Physiotherapist, Llandough Children's Centre)

"Very useful for parents. Excellent!" (Nurses on the Neonatal Outreach Team)

Thank you to all who were involved in the publication of these booklets – I will be recommending them to everyone!

Sian Howells
Senior Physiotherapist
Children's Centre
Llandough Hospital
Cardiff



HERE AND THERE

FORWARD -

Bath Pain Management Unit Launches Adolescent Newsletter

The Bath Pain management unit has been running three-week residential programmes for adolescents since 1999. We have seen over 200 adolescents in this time.

The programmes were set up for adolescents whose experience of chronic pain was making a significant and detrimental impact on their developing lives. Adolescents reported reduction in school attendance, sporting activities, socialising, and changes in sleep and eating patterns, all of which influenced their mood and physical health.

The programme is run by an interdisciplinary team comprising of Physiotherapists, Clinical Psychologists, Occupational Therapists, Specialist Nurse and Paediatric Rheumatologist and Specialist in pain medicine. The programme focuses on returning adolescents to school/college or to start work, return to age appropriate activities, so adolescents can live a full and satisfying life with the ongoing presence of pain.

The programme content comprises body conditioning, activity engagement, mood management, healthy living information and pain and medication education. Six adolescents are invited onto each programme with their accompanying adult. Our data shows their physical functioning, anxiety and depression and schooling are all significantly improved at three-month follow-up.

The unit is launching its first ever edition of FORWARD, the adolescent service newsletter. It has two purposes to inform our colleagues of what we do on our programmes and to provide a forum for our adolescents and parents to share their tips for success and stories of their progress. If you would like to be added to our mailing list please send your name and address to jane.clarke@rnhrd-tr.swest.nhs.uk (details protected by data protection act). For more information about the unit visit our website www.bath.ac.uk/pain-management.



THE BATH TEAM



APCP at CSP CONGRESS 2005

Come and join us on
FRIDAY 7th OCTOBER
at the International Conference Centre
in Birmingham

APCP's day at Congress will include talks on
Chronic Fatigue Syndrome and Pilates for Children.

As well as networking and catching up
with old friends there will also be the
opportunity to attend APCP's AGM.

Please look in Frontline for further information.

Tickets for day attendance are available.



Queen Margaret University College
EDINBURGH



Paediatric Physiotherapy and Occupational Therapy:

A critical approach to advancing specialist knowledge and practice

Run as part of the MSc Physiotherapy programme

This block attendance module will run from September 2005 – May 2006 for part time students only

The module critically analyses the issues relevant to clinical effectiveness and explores and evaluates:

- the principles of good communication in various settings with children, families and other professionals
- how psycho-social issues influence interventions with children
- the legal & ethical issues in relation to working with children.

This module has been developed in association with the Association of Paediatric Chartered Physiotherapists

For further details contact: Gill Baer (gbaer@qmuc.ac.uk) or Fiona Coutts (fcoutts@qmuc.ac.uk)

Details of the full MSc programme can be obtained at <http://healthsciences.qmuc.ac.uk/LEARNING-RESOURCES/postmsc/home.htm>

THE APCP RESEARCH GROUP REGISTER

If you would like to be a member of the APCP research group, please fill in the form below and return it to **Jeanne Hartley, Research Officer, Physiotherapy Department, Great Ormond Street, London, WC1N 3 JH**. This information will be used to inform you of reseach study days and help us to learn more about our members' research interest.

Name

Contact
Address

Post Code

Tel. No.

Fax No.

E-Mail:

What are your research interests?

Are you undertaking any type of research project small or large? **YES?NO**

If so please give a brief summary . . .

Would you be happy for other physiotherapists with similar research interests to be put in touch with you? **YES/NO**

Thank you for completing this form.



DON'T FORGET
TO BOOK YOUR PLACE
AT CONGRESS FOR
7TH OCTOBER

- REMEMBER THIS IS
PAEDIATRIC DAY



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CONFERENCE EDITION

In this issue :

Consent – the Welsh Vision

Perceived Efficacy and Goal Setting Systems

Choice – Theory and Practical Application

Collaborative Practices in the Community

The Hopes and Choices of Parents

**Questionnaire Survey – Treatment
Principles Used in the Management
Of Cerebral Palsy**

