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Editorial

By the time you read this publication many of you will have been to the NTE and are hopefully buzzing with new ideas and have had the opportunity to network with fellow REs, therapists and medics. For those of you who weren't able to go for various reasons, I hope this publication will give you some inspiration in your daily work, or maybe will encourage you to write about a certain experience you have had in your service.

We have a wealth of reading matter and I am grateful to all who have taken the time to write, with the various different styles of writing. Hopefully you can all see that you too have something to add? I have tried to lead by example and have reflected on two advisory assessments that came to the Whizz-Kidz centre in January: nothing out of the ordinary, just two cases that stand out in my mind. You must all see cases like these that stick in your mind just that bit longer than most? Well, why not write about one of them and tell others why they were different, or why they made you think out of the box?

We also have a very thought provoking reflection from Martin Moore whom many of you will have met in his various lives within the world of special seating. Also some excellent new product updates from Activate, MERU, Pride, and Theraplay.

Hopefully by now you will all have realised that this edition has a theme of paediatrics. I feel we have achieved what we set out to do in this edition, and we always hope to have a theme for each publication to make it a focus for those who want to write, and a useful tool to refer back to. We have a very useful table of powered chair specifications produced by my colleague Anne Harris who has a wealth of experience in working with very young children needing powered mobility. Also there is a refresher on the importance of using the right accessory and hip belt for the paediatric client, written by Stephanie Bayley. Both these pieces should be useful as a reminder and a quick reference point.

There is a section on wheelchair training. Again, we must all come across clients who would benefit from attending a training course to get the most out of their chair and to reach their optimum level of independence. Hopefully there should be a course close enough for most children to benefit from. If not, why not contact the relevant organisation to let them know you have a need locally.

The theme for the next publication will be the Warwick NTE and we warmly welcome and encourage anyone who wants to write on their experience of the event. Any good pictures will also be appreciated.

I would like to say an enormous thank you to Olwen Ellis, who is now my right hand woman and has taken over the role of administration support for the publication (and so much more). She has relieved Patricia whose duties with the NTE demanded so much of her time – thank you Patricia for your help in the past.

I have an excellent editorial team to work with and that is the only reason you have this in front of you today. Thanks to Barend, Helen, Jane, and Kevin. The twice yearly newssheet will now be in the very good hands of Jane Harding. Please send in any diary dates or notices for this to Olwen.

Happy reading: I hope you find something in this edition that makes you want to read on. I have written my editorial on Easter Monday, as it was that or mowing the grass, so this obviously won (you can't eat Easter egg and cut grass at the same time!).

Please note we are now using the ISSN number on the front cover. This is our first step towards becoming a Journal – very exciting times ahead, so please write away!

Joanne McConnell, April 2007

Communications Sub-committee 2006/7

Editor: Joanne McConnell

Barend ter Haar, Jane Harding (Newssheet editor), Helen Hislop

Editorial Assistant: Olwen Ellis

Deadline for copy for the Autumn 07 issue is September 7th 2007, and the focus will be the National Training Event 2007. The aim of Posture & Mobility is to keep members in touch with current events in the world of posture and mobility and to provide the opportunity to share ideas and learn of new initiatives. Articles submitted can be between 500 and 2,000 words. We also welcome contributions for Signpost, plus reviews on books, reports and products. For details on format etc, please contact **Olwen Ellis** at **olwen.ellis@pmguk.co.uk** or **Telelephone: 0845 1301 764**.

“State of the Nation” – Letter from the Chair

It is a difficult time in the NHS. Money is ever tighter and so we are constantly having to make savings, increase efficiency, reduce waste, etc. This doesn’t just affect those working in the NHS, but has a knock-on effect on those in the commercial and voluntary sectors. Of course most crucially it affects the service we are able to offer to our clients who are frequently denied the equipment they need or the delivery of this equipment is significantly delayed.

Despite these difficulties there seems to be a steely resolve, certainly in my own area, to fight the good fight. Perhaps this is because we know our clients. Perhaps it is because we know that problems won’t go away, and that sooner or later we are going to have to deal with them. Perhaps there are many reasons.

Whatever the reasons might be, it is worth knowing that moves are afoot within the Department of Health to change the way in which our services are structured and run. Whether this is for the better or not only time will tell.

The Transforming Community Equipment and Wheelchair Services project started in the Autumn of 2006. I have been privileged to attend the steering board meetings for this project on behalf of the PMG. I have two “companions” from our field: Jill Craddock from Bromley Wheelchair Service, representing the Chartered Society of Physiotherapists, and Brian Smith from RREMS in Newcastle, representing the National Wheelchair Managers’ Forum. In addition, Bernadette Simpson, whom you may remember from the “Out and About” Department of Health report on wheelchair services, is also in attendance.

The project aims to develop a new model which will best meet the needs of the client while at the same time cutting costs by improving efficiency. The cynical amongst us will believe that only the latter aspect will come true and indeed I can offer you no solace at the time of writing. The outline business case for community equipment is complete, but focuses heavily on the smaller, cheaper items of community equipment, with the client being viewed more as a consumer. Standing frames, static seats and lying supports are classed as complex equipment and are referred to only briefly. We will not know how these are to be provided until a more detailed report is issued.

The outline business case for wheelchair services is currently under construction so we will know more in the coming months. I am not at liberty to discuss detail at the present time, but can say there are currently two models under consideration. I shall endeavour to keep you up to speed with developments.

Funding opportunities from PMG

You may have noticed recent correspondence indicating that the number of application rounds each year for the PMG Research & Development fund has risen from one to two. Please consider taking advantage of this. There is so much work to do and not enough people to do it. We need to increase the evidence base to support the work we do and here is a golden opportunity to get started.

You should also have received notification of an additional PMG training bursary fund (separate to that available for conference). There are many courses out there which are of significant value, but which might be out of reach due to limited training monies. If you are in this position, please consider applying to this new bursary fund. So far we have had one application which we have been able to support in relation to a post-graduate course in posture management.

With kind regards,

Dave Long, PMG Chair, April 2007

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Making a Difference

Helen Yarrow, PMG Research & Development Sub-committee

I'm not a physio, I'm not an OT, I know nothing really about rehabilitation, prosthetics, nor am I an expert on seating – but I am a member of the R&D Sub-committee! It has been a real privilege to be part of this committee for a number of reasons – to read about some of the pioneering work that is carried out, to be part of a group of people who can encourage and support research & development and to see first hand the enormous commitment, dedication and enthusiasm you all have in working towards improving the lives of the many people there are with postural and mobility concerns.

So what do I bring to the table?

Well, as the carer of a profoundly disabled (cerebral palsy) young person who is, to say the least, challenging when it comes to special seating, I hope I bring a different perspective. Perhaps a reminder of what it's like living with, being a carer for, someone who is 100% dependent on others.

And so, having reviewed research projects, listened to experts in their fields, and read a reasonable amount (why is there always so much paper work!) I just wanted to write and thank you. Your research, dedication, commitment and enthusiasm *do* make a difference. Perhaps I can share the following article with you. It might give you an insight into what it's like raising a child with a disability.

"When you're going to have a baby, it's like planning a fabulous vacation trip to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum, the Michelangelo, David, the gondolas in Venice. You may learn some handy phrases in Italian; it's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. A few hours later, the plane lands. The flight attendant comes and says, 'Welcome to Holland'. 'Holland?' you say, 'What do you mean Holland? I booked up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy.'

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place. So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around and you begin to notice that Holland has windmills, Holland has tulips, Holland even has Rembrandts.

But everyone else you know is busy coming and going from Italy, and they are all bragging about what a wonderful time they had there. And, for the rest of your life you will say, 'Yes, that's where I was supposed to go. That's what I had planned.'

And the pain of that will never, ever go away, because the loss of that dream is a very significant loss.

But, if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland."

Most parents' early memories are of their child's first words, their first steps; mine were different. In fact my most vivid memory is of the first day I pushed Sarah in a wheelchair – to this day, some 18 years later, I can remember exactly where I was and exactly how I felt. Devastated. And so, if us parents are a bit stroppy or emotional at wheelchair clinics, if clients aren't always appreciative, it's not because we don't like you, or we don't like the chair, or what you are offering us – it's because we'd rather not be there at all – it wasn't part of our plan in life.

But the work you are all doing makes it just that bit easier to forget about Italy and enjoy Holland. And so again, on behalf of the very many people you give support to, thank you.

Mummy Wrong Room: Advisory Assessment and First Trial in a Powered Chair

Joanne McConnell, Senior Mobility Therapist, Whizz-Kidz
Email: j.mcconnell@whizz-kidz.org.uk

I was contacted in December 2006 by two families who had an incredible amount in common. These were two of many calls we receive at the Mobility Centres both in Birmingham and Newcastle. The strength of having such centres is their availability to provide impartial advice. Here is a brief explanation of how those two assessments went.

Both families had young boys with SMA type 2. First there was Patrick aged 23 months who was a twin with an older brother aged 4. His family came from Sale in Cheshire and they were willing to travel to Birmingham for the correct advice and the chance to see whether or not their son could use a powered chair.

Next there was William who was just 18 months old and is an only child. He lives in Warwick and came along with his mum and local paediatric physio for advice on whether or not he would be able to use a powered chair.

I had decided to assess both children on the same day at the Birmingham Centre as they had so much in common. I invited Permobil along to trial the Koala with them as we have had so much positive experience with very young children in this chair. We also assessed them in the Spectra Blitz which we have as one of our assessment chairs at the Centre. We were able to offer them an assessment mid-January and both families were happy to be offered the opportunity to just let their child "have a go" in a non threatening environment.

Patrick *(pictured above)* is a very bright little boy who has become very frustrated by his lack of mobility. He has to sit and watch his twin brother and older brother play: he can join in as long as they play near him, but when they move to another room to continue their game, he calls out to his mother, "Mummy wrong room". Of all the kids I have helped since being at Whizz-Kidz and of all the cases I knew when I was a paediatric OT in the NHS, this one line from Patrick is what sums up for me why I do the job I do.

After Patrick had only been in the chair for a few minutes he was driving it around. To start with he was slow and nervous and he wanted his mum by his side, but he soon wanted to go faster and further. He wanted to go round in circles, because he could! Yes, he wanted to bump a few times, but only because he thought it was funny and he had seen his brothers do this – run around and around in circles, chase each other until they were hot and out of breath, then bump into each other or bump down on the floor like a sack of potatoes.

This first experience of independent mobility was all of those things for him and much more. His mum was overcome with emotion: "As we drove here today," she said, "I told myself, it doesn't matter if he can't do it – at least we will know, and maybe he will be too young to understand it." Patrick did not need teaching; he knew exactly what to do. All he needs is a chair of his own to gain experience in and his skills will develop daily.

Mum filled out an application form to Whizz-Kidz for funding and he is now on our waiting list. She has also applied to other charities and will wait to see whose list Patrick reaches the top of first. Even if Whizz-Kidz don't end up funding him, we have played a crucial part in the assessment process for Patrick. He does not meet the criteria of his local service as he is too young. Patrick left the Centre with balloons and stickers and lots of smiles. Mum left knowing that her son would soon have the independent mobility he needed to keep up with his brothers.

During this first assessment, William *(pictured on page 8)* had arrived and had been sitting watching how clever Patrick was. He was so interested in what was going on: he sat in his buggy and stared. William was five months younger than Patrick and still looked very like a baby sitting in his buggy with his dummy and comfort blanket. He was clingier to Mum and it took a few attempts to sit him in the Koala, but as soon as we walked away and left him with just his Mum, he began to hold the joystick. Within five minutes he too was having a go at driving the chair. He wasn't as quick to perform as Patrick, but developmentally he was five months behind and he had not had the advantage of watching siblings move and play; he doesn't have as much to want to move for. Nevertheless he still moved independently and smiled when Mum clapped and praised him. He tired very quickly and ten minutes was more than enough for one day, as you would expect of a toddler of 18 months. William is now on our waiting list too and has also applied to the Jennifer Trust and Joseph Patrick Memorial Trust (JPMT) for help.

Some may argue that 18 months is too young for powered mobility, and from my own experience as a mother, my daughter didn't walk until 22 months. But she had the ability to bottom shuffle around, so she still had mobility and was still learning crucial skills by moving about. Others may ask what about the risk? And yes of course there is a risk, but every day you let your toddler walk outdoors there is a risk – they bump heads, they fall over, they get lots of cuts and bruises, but that's how they learn. We all know of a child or two, maybe even your own child, who has fallen down the stairs; yes it was an awful experience and probably a stair gate was fitted the very same day, but the stairs weren't removed!

Why the Koala? I'm not saying it's the only chair for young children, but it fits well into their lifestyles. It worked for both these children as it has seating that goes down to 25 cm x 27 cm. It has very good standard seating that will often do away with the need for any additional seating and it has a seat to floor height of 41 cm. This means this chair will get under nursery desks and enable the child to be at the same height as his or her peers. It also has a riser for other activities.

The other chairs that I have found useful for such small children are the Blitz and the Skippy. These also are lower to the floor and have smaller seat options, but neither can have a kerb climber fitted and are both rear wheel drive. Although it is not an immediate need for a child of 18 or 23 months to climb a kerb, it is still a skill that they will need to be working towards if they are to be independent users as an older child.

Basically the most important feature of any chair is that it gives children independent mobility and the chance to keep up with their peers. Also that it is not just an adult chair with paediatric sized seating.

This piece of writing was never meant to be a lecture, just a factual case study of two children who wanted an advisory assessment. The biggest message I wanted to get across was how it can make all the difference to the families we see, and the lasting memory I have of that day is "Mummy wrong room".

Have you confirmed your PMG membership details online? Have you cancelled your Standing Order to PMG?

At the time of writing, approximately 400 members have visited the PMG website to confirm or amend the contact details we currently hold for them on the membership database. **If you have not already done this, could you please do so immediately?** You will have received either an email or letter containing your **unique membership identifier** in March/April 07.

The new PMG membership renewal and joining system is about to be launched online in June 07 (see enclosed flyer) and if you have confirmed your contact details as requested, all you will need to do when renewing your PMG membership next month is pay!

While we are talking money, do you still have an annual standing order in favour of PMG? If so, **could you please contact your bank to cancel it immediately**, otherwise you will be paying PMG an additional £10 in January 2008.

We would be very grateful for your co-operation during this major overhaul of the membership administrative system which is being designed for you to manage your own membership details/subscription payments.

Many thanks, **PMG membership secretariat (email: info@pmguk.co.uk)**

Indoor/Outdoor Powered Wheelchairs for Younger Children: A Useful Comparison of Sizes and Additional Features

Information table kindly produced by Anne Harris, MSc DipCOT, Mobility Therapist for Whizz-Kidz
Email: anneh.whizz-kidz@btconnect.com

Name and manufacturer	Height to seat base (top of cushion)	Seat width	Seat depth	Riser & riser heights	Tilt in space	Obstacle climbing ability	Passed crash test	Drive wheels
Corgi Power (Activate)	42-47 cm	26-40 cm	19-45 cm	yes	powered	50-100 mm	yes	rear or front
Balder Junior (Balder)	(38 cm)	30-35 cm	35-40 cm	38-82 cm	powered	70 mm	yes	front
Wizzybug (BIME)	33 cm	24.5 cm	15.5-24.5 cm	no	manual	30 mm app	no	front
Kariboo (DSC Joncare)	51 cm	36-47 cm	35-45 cm	51-71 cm	powered	85 mm		front
Skwirrel (DCS Joncare)	to floor	22-30 cm	to order	12-84 cm	powered	100 mm	yes	front
SnapDragon (Dragon Mobility)	to floor	41 cm	custom made	yes	manual	50 mm	yes	front
Blitz (Invacare)	43 cm & 45 cm	25 cm to 38 cm adj	25-30-38 cm	no	powered	50 mm	yes	rear
Spectra Plus (Invacare)	45 cm & 49 cm	31, 38, 43 cm	27-45 cm	30 cm	powered	100 mm	yes	rear
Kid Power (Lomax)	51 cm	25.4-35.6 cm	25.4-35.5 cm	no	no	100 mm	yes	rear
Powermax (Lomax)	51 cm	30.5, 35.6, 43.2, 45.7, 50.8 cm	30.5, 35.6, 43.2, 45.7 cm	no	yes	100 mm	yes	rear
T Max (Lomax)	51 cm	20-30 cm	20-36 cm	no	yes	100 mm	yes	rear
Champi (Meyra)	(59 cm)	38-51 cm	39-48 cm	no	no	50 mm		rear
Hippo (Moving people)	(48 cm)	25-38 cm	25-40 cm	yes	yes	60 mm	yes	front
Skippy (Otto Bock)	43 cm	26-38 cm	30-37 cm	no	powered	50 mm	yes	rear
Koala (Permobil)	(41 cm)	25-30-35 cm	27-37 cm	41-71 cm	powered	60 mm	yes	front
Playman (Permobil)	(53 cm)	25- 30-35 cm	27-32-37 cm	25-80 cm	powered	70 mm	yes	front
Dynamo 1107 (Pride)	45 cm + up to 7.5 cm	25.5, 30.5, 41.0 cm	25.5, 30.5, 41.0 cm	no	manual	60 mm	yes	front/mid
Bobcat (Smile Rehab)	to floor	custom made	custom made	yes	manual	50-100 mm	no	front
F45 (Sunrise)	48 cm	30 cm upwards	30 cm upwards	no	no	50 mm	yes	rear

This information has been gathered from the manufacturers and was correct at time of going to print. If you have any queries we advise that you contact the manufacturer for clarification.

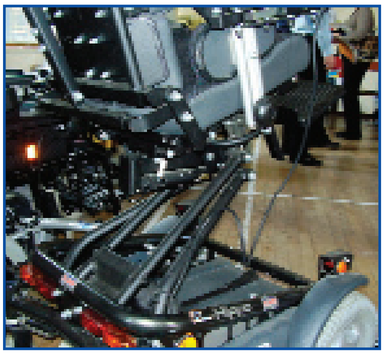
A Comparison of a Variety of Paediatric Wheelchairs

Geoff Harbach, Clinical Technologist, West Midlands Rehab Centre, Selly Oak, Birmingham, B29 6JA

This document describes the learning gained from attending the wheelchair training day organised by the Birmingham Whizz-Kidz Resource Centre on 8th March this year. The event took place in the Selly Oak Methodist Church Hall very close to the Whizz-Kidz Centre, which is just over the road from the West Midlands Rehab Centre in Selly Oak.

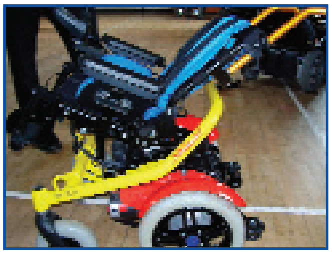
A number of paediatric, junior, teenage, and adult chairs from a number of manufacturers and local suppliers were presented to interested therapists, engineers, parents, carers, and potential clients.

The following notes form part of my CPD activity log, and highlight certain features of the presented chairs which caught my attention. The chairs are not presented in any particular order and no preference should be assumed from their order in the list.

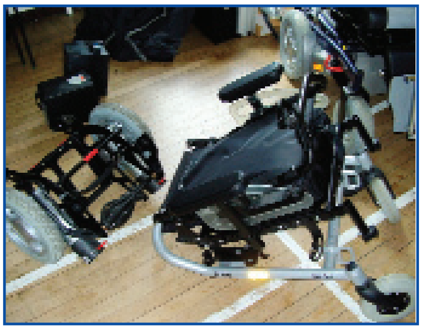


The Moving People HIPPO is a front wheel drive chair with electric seat raise, back support recline, seat tilt and foot supports. It has a pivoted trailing caster axle. It has lights, P&G Pilot loom and Omni controller. The seating is standard issue.

The SPECTRA BLITZ is a rearwheel drive compact chair for children, with powered seat raise and seat tilt. This is a bit chunky looking at the front and is slightly narrower and shorter than the Spectra. This chair had separate foot supports.



The Otto Bock SKIPPI is a brightly-coloured kiddies' chair with large range of recline. It will take a client weighing up to 50 kg. It is very chunky, and can accommodate seating systems. I think the power section dismounts from the seat section. It has removable batteries. This one uses a CURTIS controller. Note the extended push handle.



The Otto Bock A200 is for older children/ adults and has a demountable power section with removable batteries and a fold forward back support to make it easier to get it into and out of vehicles.

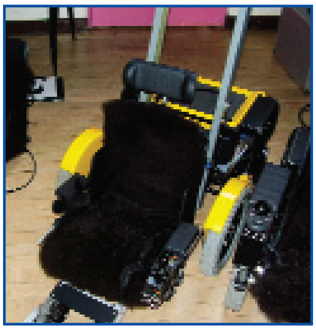
The Moving People PUMA is a large outdoor chair available with front or rear wheel drive, and with an extended chassis. It can be fitted with electric options including seat raise and tilt.

The Pride Mobility JAZZY 1103 is a mid wheel chair with front anti-tippers, and is very manoeuvrable with a pivoted trailing rear caster axle. It has a nice back support angle release lever, making it easy to change the angle of the back support, but you would need trunk control, otherwise you would just fall backwards.

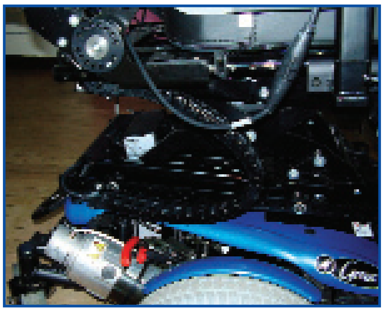
The Permobil KOALA is a paediatric powered chair with seat raise. Note the Pilot attendant remote and seat controls on the left hand arm support. It has a single piece foot support, and a very wide front stance

The Permobil CHAIRMAN 2K is a chair which will perform sit-to-stand, and everything in between. Note the seat control on the right hand arm support. This wheelchair has been designed for the older/larger teenager/adult.

The dragonmobility wheelchairs offer an unusual design of front wheel drive chairs with a demountable seat raiser system based on a tall frame with a rack. The foot support is pivoted so that when the chair approaches the floor, the footplate and support stem start to fold out into a platform so the seat really does go right down to the floor, which is a really neat idea. They make their own control system which is based on torque demand rather than speed, although it can be set to a velocity profile. I think the one I drove would have benefited from being tuned better to my requirements, as it tended to run on more than I am used to, but then, I am not used to this sort of system. It is great for the right people. It felt a little unstable as it had very soft suspension The client sits right at the front and all the weight of the chair is at the back. It does have anti tippers at the front though. The chair provides the client with very good access to the floor and higher up places. Dragonmobility could make a switch output module if requested.



The SNAPDRAGON Paediatric chair. Notice that the seat is right on the floor! The standard seat can be replaced by a standing frame, which is good for therapeutic purposes whilst still allowing mobility. The SnapDragon will take Leckey seating, and can travel at up to 4 or 6 MPH.



The Sunrise Medical GROOVE powered chairs have a ladder frame type seat raise. Note the dial indexed back support angle adjustment, and the very nice roller chain cable management system. These have a very nice compact and neatly engineered system. Different types of seat module just slide into the seat frame. The seating is fully adjustable. This unit had a Delphi controller. They can be fitted with a kerb climber and independent foot supports depending on model options.

The Invacare STORM can achieve a 20” seat width and can take a 32 stone client. It has a very good seat to ground height, and there is plenty of room at the back for a vent tray or similar.

This concludes my brief description of the chairs I saw. Whilst I was at the event a number of clients came in with their families or carers and were able to try out the different chairs and talk to the representatives in a calm, quiet, and relaxed atmosphere. This training day was an excellent way to explore the relative merits of a number of chairs, and I would recommend it to others who want to develop and maintain their knowledge of non-NHS powered chair options.

Luddite’s Corner

“New technology is the stuff that doesn’t work yet.”
Richard Adams (author of Watership Down)

“Hell is very likely to be modernisation, infinitely extended.”
Tom Stoppard (playwright)

Supportive Seating and Community Inclusion: Making Hidden People Visible

Helen Sims, Supportive Seating Programme Manager, Motivation Sri Lanka

The UN Convention on the Rights of the Child (UNCRC) includes the rights of children to education, association and relationship-building with other children, and to normal activities expected for early childhood development. The convention also guarantees physically disabled children the right to enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance, and facilitate the child's active participation in the community.

This article concentrates on the positive impact supportive seating has had on the quality of life of disabled people in Sri Lanka. It includes case studies before and after receiving a supportive seat and looks at developments in health, community access and family integration. Supportive seating can literally be the means by which children can get off the floor and out into their communities. For those in need, a supportive seat is the pre-requisite for accessing their basic rights.

Awareness and understanding about the needs of children and adults with severe physical difficulties in Sri Lanka remain poor. In every corner of Sri Lanka there are people who, through severe physical disability, are excluded from society.

Sri Lanka is an island of 20 million people situated off the southernmost tip of India. With an area of 66,000 square kilometres it is about the same size as Ireland. Geographically, Sri Lanka is diverse: the central hill country rises a little south of the centre of the island reaching its peak at 2524 m; the flat plains extend from the hill country all the way to the northern tip of the island and this area is very dry; the entire island is surrounded by a coastal plain.

Undoubtedly one of the most beautiful islands in the world, Sri Lanka has encountered many difficulties in recent history. The civil war in the north and east of the country has affected the lives of the people who live there for the past 24 years, killing at least 60,000 people and injuring many more. On the 26th December 2004 Sri Lanka received the full brunt of the Asian Tsunami: 40,000 people lost their lives and many thousands were injured and disabled.

Motivation, a British-based organisation, has been working in Sri Lanka since 1997. Through the design of locally-made, low-cost postural management equipment, Motivation aims to build the capacity of local partner organisations to improve the quality of life of people with disabilities. Services in Sri Lanka for children and adults with moderate to complex postural management needs are scarce with understanding about the specific needs of people requiring postural management solutions very limited. Several national and international organisations have been attempting to work with people with postural management needs. However, their efforts have been hampered by the lack of specialist knowledge, the non-availability of appropriate products, nor the service structures with which to supply them. The lack of products and services has left children and adults in all areas of the country living with a complete lack

The Sarath seating system is available with a choice of bases depending upon the specific environment the user lives in.

of dignity. Unable to support themselves, many are only able to lie on the floor or in beds for hours on end, without being able to participate in family life. The children cannot attend school or interact and develop naturally as children.

Motivation's supportive seating programme has brought into production a range of low cost supportive seating units. The seating is designed to clip on and off either a static or wheeled base. This means that the supportive seat is suitable for use even in the most constricted of spaces. The three-wheel base of the chair makes it appropriate for use on rough ground, mud, and sand, therefore making it usable on Sri Lanka's diverse geographical terrain.

Through dedicated training, covering the clinical and technical aspects of supportive seating, professional seating services have been established in four key locations throughout Sri Lanka, giving a greater number of families access to the services they require. As the programme in Sri Lanka is developing, we are starting to address the 24-hour postural management needs of the service users through appropriate lying and standing solutions.

A combination of appropriate product provision, coupled with the establishment of professional supportive seating services, has started to have a positive effect on the quality of life for children and adults with disabilities in Sri Lanka. Getting up off the floor and out of their homes has made this population much more visible. This has led to increased awareness and understanding of children and adults with severe and complex postural management needs.

Case Study 1

Achini has cerebral palsy. She was abandoned by her parents at birth. For the past 14 years she has been brought up by her elderly grandparents. She lives in a tiny village nestled in the tea estates bordering the Sinharja rain forest. In this remote part of Sri Lanka there is no road access – it is a 10 km hike to the main road.

As Achini got bigger and her grandparents got older it became almost impossible for her to be moved around. Achini would spend hour after hour lying on the floor or slumped in a chair. With no way to move her she was increasingly marginalized from community and family life.

In November Achini received a supportive seat. From that moment her life changed. With the ability to sit up, she discovered that she could do many things. She is now able to communicate with her family, play with her siblings, eat by herself and in fact is starting to try to write. Today Achini is able to leave her house. She enjoys visits to the temple and the occasional outing to the local school. For Achini a supportive seat has been the prerequisite for access to her basic human rights.

Creating awareness of children like Achini at a rural village level helps to reduce the stigma surrounding children with disabilities as being people who had committed a bad act in a previous life. Being able to visit the local shop and neighbours helps communities to understand that those with severe disabilities can contribute positively to community life.

Case Study 2

Three year old Helindu lives in Colombo with his parents and his twin brother. When Helindu was born he contracted meningitis. He spent many days in intensive care. At six months old he started suffering from epileptic fits. His fits were extremely hard to control. He was frequently having up to 80 fits a day. Helindu has significant physical and learning disabilities.

Without a supportive seat it was extremely difficult for Helindu's parents to give him the care he required. To help him to play and interact, his Mum would have to hold him all the time. Family outings and access to any community activities were almost impossible.

At two years old Helindu's twin brother started school. With no way to sit up, Helindu had to stay at home.

Since receiving his supportive seat the change in Helindu has been remarkable. He will now make eye contact with familiar people, makes lots of attempts to communicate by babbling and enjoys playing and holding onto soft toys. His health has also improved. He suffers less frequently from chest and urine infections.

Perhaps the biggest change for Helindu is that he has now started school!

With an increasing number of school age children receiving the postural management equipment they require, schools and early childhood programmes are being forced to address the issue of inclusion of children with disabilities into educational settings.

Case Study 3

Nadara was born in 2004. A few hours after her birth she suffered a colossal epileptic fit leaving her with severe damage to the cerebellar and basal ganglia areas of her brain. Unable to swallow she was immediately provided with a nasogastric tube for feeding and not long afterwards sent home. Nadara's weight gain continued to be poor, the nasogastric tube caused her much distress and she was reported to cry all the time. Nadara was one of the first children in Sri Lanka to be provided with a gastrostomy and since this time her health and weight gain have increased considerably.

Once able to tolerate a greater degree of physical handling, Nadara was assessed at her local supportive seating service. She was slowly introduced to a supportive seat and began to enjoy the sensation of sitting up. With the additional support the seat gives her, she is now able to participate more actively in meal times. The chair, which is specifically designed to be low to the ground, gives Nadara ample opportunity to interact with her younger brother and sister.

Contact details:
Motivation Charitable Trust
Brockley Academy, Brockley Lane
Backwell, Bristol BS48 4AQ
Tel: +44 (0)1275 464012
Fax: +44 (0)1275 464019
Email: info@motivation.org.uk
www.motivation.org.uk

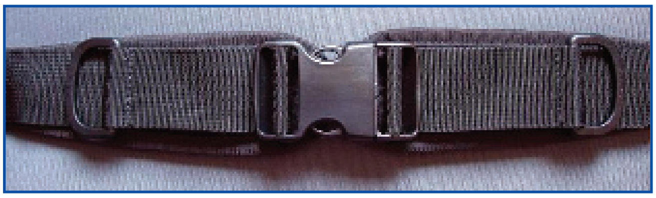
Accessories for Children

Stephanie Bayley, Area Manager, BES Rehab Ltd

Paediatric seating is not about providing adult equipment in a smaller size. Bodypoint has long been at the forefront of well thought-out secondary postural support, and their Paediatric belts and harnesses are supplied with the smaller sized body and hands in mind.

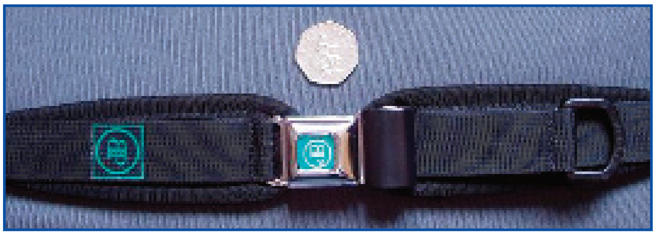
To start with, the Bodypoint hip belt buckles are designed to provide options for different needs. For example, the plastic push button is small, flat and discreet, and can be undone with little strength.

The side release buckle is typical of many 'back-pack' style bags and accessories, so this is very popular with children who are starting to feel a bit more grown up.



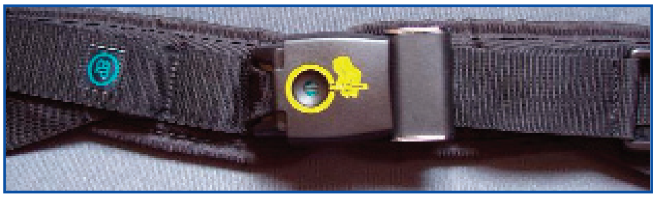
The black plastic is less obvious than buttoned buckles and takes a little more dexterity and strength than the push button to open.

If you need something stronger, maybe for a child who has strong extensor thrusts, the small metal push button is small enough that it doesn't overshadow the overall belt, but its shiny chrome finish is bright enough for children and carers to see easily, which is particularly useful for the partially sighted.



Unlike the larger version, this push button is not spring loaded, so it won't take a child by surprise!

If a child has a tendency to fiddle with a buckle, whether it be a deliberate attempt at opening a belt at inopportune times, or due to spasms or involuntary muscle movements, the metal push button can be supplied with a security cover. This slides over the buckle and holds firmly in place. In order to undo the buckle a pen or small screwdriver can be used to 'pop' the buckle open.



If additional upper postural support is required, Bodypoint provides a choice of Shoulder Harnesses or the Stayflex™ Anterior Trunk Support.

The Stayflex™ Anterior Trunk Support is a dynamic postural support designed to combine the benefits of stability and movement with comfort.

The Stayflex™ utilises a special elastic material, which allows the fabric a regulated amount of stretch in the upper section. This allows children to lean forward to complete tasks such as eating, playing/working at a computer, etc, but then helps them to straighten back up. This can be particularly useful for boys with MD. However, the lower section fabric stretches less to keep the support in position and not let it 'ride up' whilst still allowing movement for breathing. By permitting a certain amount of flexibility it can thus prevent unwanted movement.

The Stayflex™ is supplied at the base with quick-release swivel buckles that allow the fitting line to be smooth and not 'ruck-up'. There is also the choice, in all but the smallest size, of a front zip for easy removal. Aesthetically, the Stayflex™ looks more like a small waistcoat than a positioning device.

Bodypoint products are available from BES Rehab Ltd
Tel: 0845 1300 237

Wheelchair Skills Training

Roy Wild, Association of Wheelchair Children (AWC)

The Association of Wheelchair Children (AWC) is a specialist national charity providing expert mobility training and advice to wheelchair-using children and their families across the UK and Ireland. We teach children useful, practical skills, such as the management of kerbs, slopes and steps enabling them to move safely and confidently about their homes and neighbourhood. Our mobility courses are free of charge.

AWC has two training teams: one based in London and one (AWC North) in East Yorkshire. We can run courses wherever there is a need and most courses are now requested by physiotherapists, occupational therapists, or parents *(see dates on page 47)*.

We run courses for young people up to the age of 18 and have worked with children as young as two. We usually run a manual wheelchair course over two days and we bring extra wheelchairs along so that parents and siblings can join in with the games. We cover road safety, kerb work, slopes, emergency evacuation procedures, and an introduction to wheelchair sports.

The courses are aimed at the more active, independent wheelchair user, but we have worked with children with a wide range of abilities and find that there is something in the course for everyone. We have even started including an element of wheelchair dance in the courses. AWC also runs courses for powered chair users and professionals' workshops (for those working with young people with disabilities). Our patron, Ade Adeptian (he did the wheelchair dance sequence on BBC 1 and presents children's BBC programmes), was one of the first young wheelchair users to come on one of our courses, and he is now a great role model for a lot of the kids that attend today.

AWC have launched their new 2007 scheme 'Moving Together'. The scheme will run in mainstream schools where wheelchair users and their classmates can take part in wheelchair sports and skills training together.

AWC North have also been piloting a number of these disability/wheelchair awareness courses in mainstream schools and these have proved very successful. The majority of these courses have been run at a school where there is a wheelchair-using pupil attending and the aim has been to give their peer group a greater understanding of the challenges faced by wheelchair users. To this end we have been taking along up to 18 wheelchairs that the able-bodied pupils can use. Some courses have been requested at schools that don't have any wheelchair users attending and these have been equally as valuable, as these pupils don't have much experience of wheelchair users and our training can help eliminate any misconceptions they may have towards young wheelchair users.

We have also worked with PE students, many of whom intend moving into a career in sports development. We have covered issues such as road safety and kerb work for wheelchair users, coping with slopes and rough ground, as well as fun activities such as wheelchair dance and wheelchair basketball. The course includes discussion on pupils' expectations and experiences of using the wheelchairs, as well as how and when to offer assistance to wheelchair users and safe body mechanics when doing so.

We go to both primary and secondary schools and have worked with up to 120 students at each school. We have also been involved in a performing arts project where wheelchair users and able-bodied students worked together choreographing two wheelchair dance sequences for a school production. We are receiving more and more requests for these courses and we now see this as a valuable part of AWC's training.

For details of courses, or to request a course, please contact Roy Wild: Tel: 0870 121 0055
email: northteam@wheelchairchildren.org.uk

For courses in the South: Tel: 0870 121 0050
email: headoffice@wheelchairchildren.org.uk
www.wheelchairchildren.org.uk

Wheelchair Skills for Long-term Training

David Sollis, Wheelchair Skills Training Manager, Whizz-Kidz

‘Child-focussed rather than wheelchair-focussed’ – that’s the founding principle of wheelchair skills training at Whizz-Kidz. Offering basic wheelchair skills, sports training and additional social and occupational opportunities has allowed Whizz-Kidz to develop a holistic approach to helping kids get the best from their mobility equipment.

With the social model of disability the schemes are led by a growing number of adult wheelchair-users who offer children first-hand knowledge and experience of life as a disabled person. Whizz-Kidz has also introduced a policy of developing young wheelchair-users to act as peer-to-peer trainers, which develops their confidence and skill level while being a huge benefit to other young wheelchair users.

The schemes are based on the *Keep on Moving* training pack, which is endorsed by Continyou, RoSPA, IRSO and the National Wheelchair Managers Forum, and consists of twelve hours of training. This can be delivered over a five-day period or over a series of weekends. This not only creates time for children to build on skills, but also offers a long-term social opportunity which can lead to a community wheelchair-focussed club. With the essential element based around fun, it offers all children – no matter what their chair, age or ability – a pathway to a more interactive and mobile lifestyle.

The *Keep on Moving* training schemes have also acted as a conduit for children to engage in other activities such as sport (e.g. basketball, rugby, archery) which has acted as a great feeder for local clubs such as Aspire Hotspur football team (North London), Knights wheelchair basketball team (Northern Ireland) and the Upside Down Club (Cambridge).

Road Safety is an essential part of the training provided by Whizz-Kidz and has developed into a recognised service by road safety officers across the UK. This has led to further opportunities in Northern Ireland, Taunton, Newcastle, and Birmingham, where road safety departments are looking to work alongside and be trained by Whizz-Kidz. This will have a considerable impact on mobility issues both for disabled and non-disabled.

With a successful 2006 and a busy 2007 in progress, the following schemes are taking place over the next few months:

Hartlepool, Ipswich, East London,
West London, Nottingham,
North Ayrshire, Horsham

Whizz-Kidz is always looking to find new areas in which to train and develop partnerships, working to create wheelchair-focussed clubs; also to give advice to parents regarding equipment.

Get in touch on 020 7233 6600
or keeponmoving@whizz-kidz.org.uk.

Childish Curiosity in Mobility

Ruth Everard, Client Funding Advisor, Dragonmobility

What single quality sums up childhood and youth? Curiosity must be a strong contender. Whether mice, elephants, dolphins, or humans, caring for young involves a large amount of protection from danger, as the infants learn what it is simply to be. So if this trait poses a danger, why is it so important? The justification is simple: in order to be a successful adult each of us must have explored, investigated, and learned from our mistakes. We must develop a grasp of the physical world around us to be able to care for ourselves; learn how to interpret what our senses tell us in order to understand our environment; and master interaction in our society to prepare us for the many roles and relationships we will be involved in during our lifetime. Without these early lessons, we would struggle to take on the independence which will increasingly be expected of us as we approach maturity and adulthood.

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Foundations to build

Independence stems from knowledge of the world, rather than from anything which can be taught in a classroom. Before we enter the classroom, then, we have foundations to build and remarkably little time in which to do this, given the magnitude of the task.

Mobility is necessary to facilitate this curiosity, and the provision of artificial mobility must address this. For a toddler in a powerchair the object is not transport, which may still be provided with pushchairs or simply by carrying them, but the exploration of the environment and development of skills which will result in being able to access the world. Pulling all the saucepans out of the cupboard, looking at things out of windows and playing hide and seek all involve autonomous movement. An adult watching a child is incapable of imagining where and how far this inherent curiosity will drive him.

Exploration

Developmental milestones are consequently delayed when mobility is impaired, and the reason for this is obvious: the fewer the opportunities to discover the world, the greater the loss of experience. Moreover, that loss compounds on itself. After the age of two it may be impossible to reverse the damage done: the child's peers have already left him far behind and there is simply no time to catch up. Studies of adults show that it is possible to identify individuals who were immobile at this critical time, simply by tell-tale limitations and irreversible psychological traits.

When advising parents of children whose natural mobility is impaired, it is necessary to acknowledge the instincts upon which these parents are acting. In guiding them, it is necessary to counter and advise against behaviour which will unwittingly damage the child and the family in later life. The parental instinct is to protect, but this is designed to act in opposition to the child's instinct to explore. If exploration is thwarted by the physical limitations on the child, there is an imbalance. The parental instinct may easily win out, rendering the child permanently limited in skill, outlook, and prospects for independence – even on a small scale – which might otherwise have been possible.

Physical movement

We develop physically due to forces in the world around us. Many children enjoy dancing as an expression of their appreciation of music, and all young children have so much energy that they need opportunities to let off steam once in a while. An ambulant child's legs, arms and torso develop control and strength from use. Similarly a disabled child can develop on a lesser scale through everyday use of what function they have. This is often used as an argument for self-propelling where it is at all possible. However, it must also be considered that movement is not the ultimate objective, but rather the means by which a child is able to develop in many ways. We may consider running uphill for half an hour a day to be beneficial to us, but that would not stop us from driving the car to the gym, as we have more to achieve in a day than simply keeping in shape. Physical exercise is not the only purpose of mobility and so a well-chosen powerchair will enable a child's body to be used as much as possible without the loss of the many other benefits of mobility at a proficiency comparable with ambulant children of the same age.

A powerchair which offers dynamic movement, complementing the child's own physical ability, in addition to seating which promotes muscle tone and reach, will promote motor skills and physical development without detriment to other equally important areas of child development.

Extended experiences

The ability to reach outside the confines of a powerchair promotes fine motor skills. Hand-eye coordination develops through curiosity and the ability to grab and manipulate objects. It is tempting to place items inside a small field of reach for a child with physical impairment, as one would for a young baby, but this consequently limits fine motor skills to only those normally achieved by a small baby. Instinctively the toddler expects to be able to manipulate more and more items in exploration of the world, and the choice of powerchair must promote this. It has been shown that feeding oneself is a milestone which follows walking in the ambulant child, so limitation of independent mobility will, in many cases, slow this important step to independence. A stationary child will only have the opportunity to manipulate those items they are allowed and games like throwing and catching are less challenging in a static position.

Visual development and spatial awareness are augmented by the environment. A newborn has blurred vision, and at first can only focus at the distance he is usually from his mother's face. Gradually vision improves so the child is able to focus and make sense of what he sees around him. Without mobility a child's interpretation of distance will be impaired, as well as understanding of texture and temperature, because the frequency of experience is limited to that which adults provide artificially. Independent mobility allows for natural development of these basic building blocks to interpreting the senses.

Broaden the experience base

It is well-known, though possibly unkind to say, that it is boring visiting a sick person in hospital. Why? Because there is very little to talk about. Similarly, if you try to write a postcard home immediately after you land at your holiday destination you will find it hard to fill the space: you have only just got there and have no information or experience to express. But if you wait two days a single postcard seems too small for everything you have to say. Now consider the baby who has yet to develop the ability to express himself verbally. The human child needs motivation to master new skills, so until mobility begins a child has little need for words such as 'hot', 'sharp', and the all-important 'no'. In the ambulant child, nouns are used increasingly with movement. How common it is to see a toddler running after the tail of an alarmed animal, crying "Cat! Cat!". Does the static child do the same? He may do so to a lesser extent, but will soon learn that it is to no avail as the reward is out of reach. As mobility continues the inquisitive child will begin to use "what?" and "where?", then "why?", "when?", and "how?" repeatedly.

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Learned helplessness

A child who cannot move is likely to be frustrated and bored and may increasingly learn to be self-centred as his needs will attract a disproportionate share of the family's attention. As character and social interaction develop, the child will use the information and interaction around him to form self-image. By provision of a powerchair which enables age-appropriate mobility the condition of 'learned helplessness' may be avoided. This condition is permanent and stems from a child being unable to express his own will or learn discipline and responsibility. Instead, he learns that his basic physical needs will be taken care of with little need for him to decide how or when, and that decisions about his daily life will continue to be made by adults around him as if he remained a baby. The most severe forms of learned helplessness may be likened in adolescence and adulthood to an artificial enforced childlike state, with little ability to take on the responsibilities of an autonomous adult. Mobility contributes to the ability of a child to express his own will and demonstrate his opinions. The temper tantrums and disobedience of 'the terrible twos' rely on an increased ability to express oneself physically, and the immobile child retains baby-like crying for basic needs without developing to the toddler level.

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Relationship building

As normal relationships grow between the ambulant child and his family and peers, interaction becomes more two-way as he develops. So, artificial mobility may enable the non-ambulant child to form these relationships. Instead of being a passive member of the household, he learns to help Mummy carry things, give toys to other children or simply follow the instruction "come here to put your coat on".

Early mobility is the key

Mobility is the key to all post-twelve-month development. Its absence will cause developmental delay which compounds disability due to the original congenital impairments, with equally permanent and damaging effects. Without appropriate artificial mobility designed for the augmentation of normal child development a non-ambulant individual is considerably more likely to develop into a dependent adult, and the full effects are unlikely ever to be reversed, even with provision of excellent services and therapy in later life.

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See page 8

New Developments from Active Design: Dysplasiometer

Carolyn Nichols, MCSP, PGDip   www.activedesign.co.uk

It is estimated that between 35 and 40 percent of children with bilateral cerebral palsy develop hip problems (hip dislocation or surgery) with related pain, difficulty with positioning, scoliosis, and kyphosis. If the hip migration percentage in a child at 30 months of age is greater than 33%, the hip is at very high risk of dislocation (Scrutton, 1997). Structural changes in the hips can remain clinically undetected until the femoral head has migrated 60% (Reimers, 1980). (A hip with a migration percentage between 33% and 75% is considered to be subluxed, over 75% is dislocated).

As a result of Scrutton's work, the review done by APCP (Chartered Society of Physiotherapy, 2001), and the MacKeith meeting, which resulted in the publication of the Consensus Statement regarding postural management for children with cerebral palsy (Gericke, 2006), there is increased awareness of the need for good hip surveillance and relevant postural management for this group of children. As part of our 2-day course on the Chailey approach to postural management, delegates learn the techniques for measuring a hip X-ray using Reimers method (Reimers, 1980) with tracing paper, pencil and ruler.

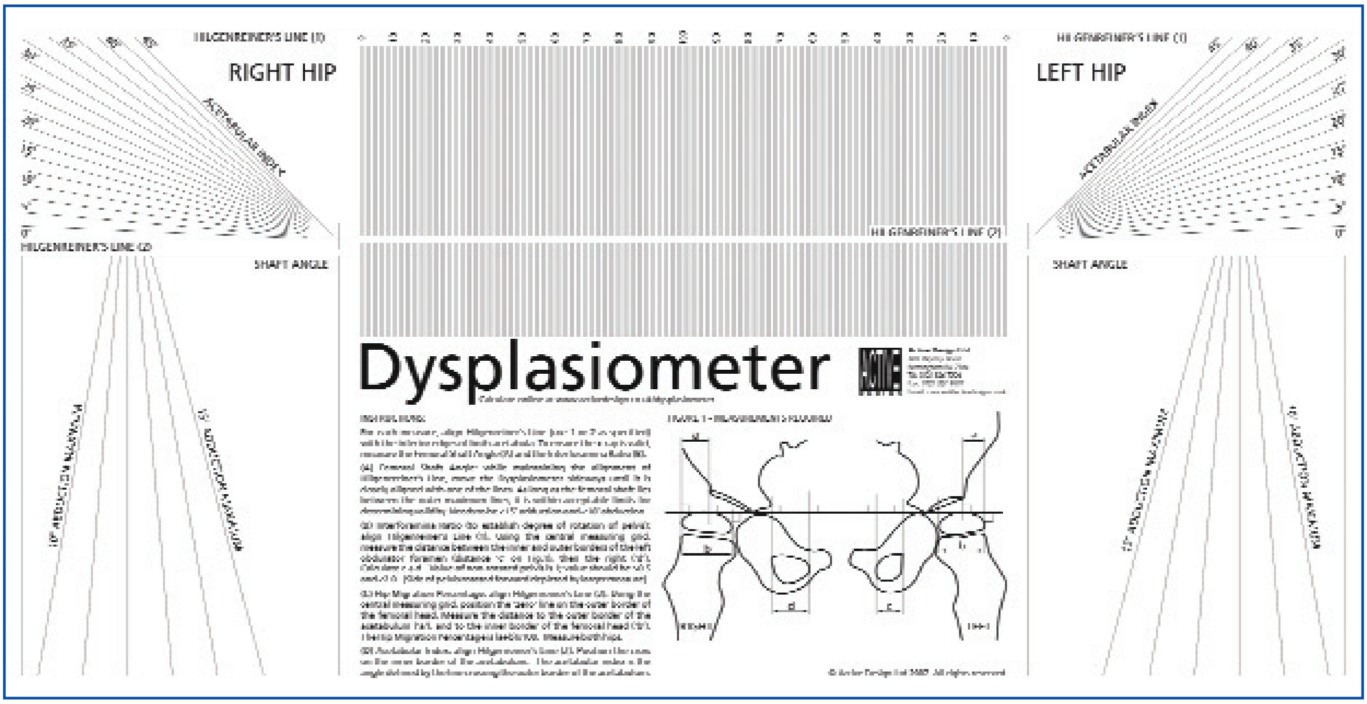
We have now developed a simple measuring tool for use by those clinicians who have access to hip X-rays, but not to on-line measuring facilities.

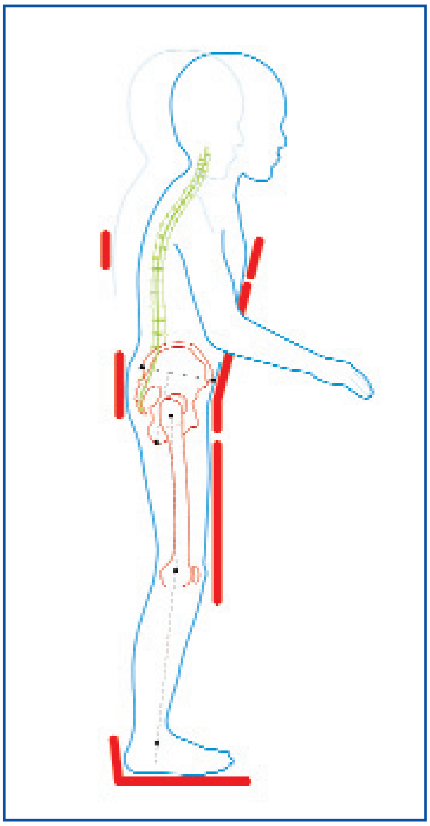
The Dysplasiometer *(see image below)* is designed to measure hip migration percentage, acetabular angle, interforamina ratio, and femoral shaft angle. Instructions are included as part of the tool, which is available free of charge from Active Design. There are more complete instructions on the Active Design Website (www.activedesign.co.uk/dysplasiometer), as well as an interactive tool for calculating your results.

The Chailey Standing Support

The Chailey Standing Support *(see image on page 22)* is now being produced, and has been welcomed in many centres nationally. It is an upright standing support, based on a biomechanical approach to the normal development of standing ability, emphasising the "lean-stand" position, with the trunk leaning slightly forward (with trunk and/or arms onto a support) and some flexion at the hips. The femurs are vertical and the line of action of the centre of gravity falls through or just in front of the feet. In normal development a child learns to stand by first being placed in lean-standing, and ability improves as the child practices shifting his weight forward and back within his base of support, and then side to side. The Chailey levels can be used to understand and analyse the components of standing ability more fully.

In addition to this being a developmentally correct position, the upright, forward-lean position is preferred





to prone or supine standing for the following reasons:

- the amount of weight borne through the hips and the legs is greater in upright standing than in prone or supine standing, therefore making a greater contribution to the maintenance of joint integrity and bone mineral density (Stuberg, 1992).
- development of ability in standing is dependent upon establishing the feet as the base of support, therefore requiring that the feet are not in front of the body or behind it, but that the line of the centre of gravity falls through the base.
- many children with cerebral palsy are not placed in upright standing because they use a total extension pattern, and often hyperextend dangerously over the posterior thoracic strap. However, when stood in the forward-lean position, with slight flexion at the hips, a child is more likely to achieve a more balanced posture, with the shoulder girdle falling more naturally into protraction, and arms able to bear weight and assist with the development of head control. We are aware that there are, however, some children who are able to hyperextend even in the forward-lean position and, for these children's standing supports, a posterior boundary / "back-stop" can be supplied.

Assessment of the child's level of ability, range of motion, and hip joint integrity are important in order to define aims of standing, and therefore standing position and duration.

Reasons for specifying a prone or supine stander (or for NOT standing, but instead using the lying position) include:

- flexion contractures at the hips and/or knees
- windswept deformity that cannot be corrected/ accommodated adequately, and use of standing is exacerbating this and related deformities
- foot deformity that cannot be accommodated
- very floppy head
- poor joint integrity
- manual handling considerations
- pain

CAPS II with Lynx backsupport

This seat has proved to be very useful and popular for those who are unable to be appropriately supported or accommodated in modular seating, but who have some postural ability and for whom moulded seating is not appropriate. These are generally people who can be placed in sitting with a reasonable base of support but who have spinal deformities which cannot be supported appropriately by a symmetrical backsupport with standard lateral supports. Once they are positioned with a fairly level pelvis on a flat or ramped cushion, the pelvic position can be maintained by the correctly adjusted seat length, pelvic laterals, footsupports and kneeblock (if used) while the Lynx material is manipulated to provide the required intimate support to the trunk. The shape of the Lynx backsupport can be easily changed, for example to accommodate growth, or a change in back shape as a result of spinal surgery, or as the client's ability changes.

Courses

We continue to run our 2-day courses on The Chailey Approach to Postural Management throughout the year at various venues. The Chailey levels are being used in the development of care pathways for complex disability as inclusion criteria, to assist in specifying appropriate equipment, and as an outcome measure. Reference can be made to the Active Design website for dates and locations of courses **(www.activedesign.co.uk/courses)**.

We follow up this course with short, practice-based workshops on levels of ability with local teams, and reflective workshops to consider how new learning has informed clinical practice.

Additionally, more technical courses can be provided, for example on the use of the CAPS II / Lynx seat, and practical advice on how to assess, measure, and prescribe appropriate standard equipment.

We can assist with defining when non-standard components are needed, and how to specify them. Non-standard modifications frequently needed in seats include asymmetrical seat cushions for leg length discrepancy, asymmetrical kneeblocks or pommels and extra-strength footsupports or kneeblocks. In lying supports we can supply made-to-measure knee wedges to support the leg with hip and knee flexion deformity comfortably; we can produce the supine lying support with a hinge at the hips to allow the top half of the lying support to be elevated to help with reflux or night-time tube feeding.

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Sharing Information

Useful websites for news about disability issues:

www.disabilitynow.org.uk/news

www.whizz-kidz.org.uk and sign up to the regular e-newsletter

www.pmguk.co.uk where you can also download previous issues of the PMG publication.

In addition to the twice-yearly PMG publication in the Spring and Autumn, we are introducing a newssheet every Summer and Winter where you can advertise free of charge the events, training courses, and projects you feel would be of interest to your colleagues. If you have something you wish to promote in the field of Posture and Mobility, please contact PMG admin for details, or send your items to:

olwen.ellis@pmguk.co.uk

Product Review of 'Bugzi'

Kirsty-Ann Cutler, Clinical lead for Birmingham Wheelchair Service

On 26th February 2007 the REs and OTs at West Midlands Rehab Centre had a demo of the MERU 'Bugzi' presented by Peter Swann from MERU.

The 'Bugzi' is a children's front wheel drive EPIC, incorporating CAPS II seating (mini and nursery sizes). It is a CE marked product. The age range is 12 months to 6 years (maximum user weight 25 kg): this is dependent on the seating since the base unit does not grow in size.

The Bugzi was developed with three main aims:

Adaptability: Adjustable seating using the CAPS II system. The controls are by a 'Dynamic' master switch unit and its own switched joystick control 'Moosi'. The control system is adaptable to accept other switches or buddy buttons very easily.

Aesthetics: It is very child-friendly with bright colours and shapes. It looks more like a toy than a wheelchair.

Transportable: It is easy to transport if required, as it breaks down into only 3 parts – the base unit, the seating unit and the battery.

There are currently 18 Bugzis out in the field, 10 of which are the initial trial units.

Its current cost is £4,000 which is inclusive of a CAPS II unit, initial set up and first year service.

Many wheelchair services are receiving referrals for powered mobility for very young children. This piece of equipment can offer the opportunity for younger children to become mobile and carry out all those activities you would expect from an ambulant child. It is adaptable enough to grow with the child and for the child to gain skills and experience of powered wheelchair use.

Many community therapists are also seeing the value of the Bugzi as a therapeutic tool and the benefits of movement for those more severely disabled children.

MERU

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Corgi: A New Paediatric Power Chair from Activate

Daniel Steedman, Activate

Activate, a specialist children's equipment supplier, has extended the range of mobility equipment on offer with the arrival of the Corgi range. The most significant development is in the area of Powered Wheelchairs. The Activate Power Chair range has a common approach giving an appropriate position to the user. Users are at a level with their peers, and have unrivalled stability for going out to country parks and keeping up with the rest of the family. The TOM and CORGI range are also available with a seat raise feature, giving access to cupboards, letterboxes, and providing a better view at events.

The Corgi Power HI-LO, as shown in the picture, has a very compact wheelbase. Having an overall width of 585 mm, there is no difficulty in slipping

through standard doorways. The seat height in the drive position is 470 mm, allowing easy access for loading. The seat raise gives a seat height of 830 mm enabling many activities at normal worktop level. When the seat is raised the speed of the motors is automatically reduced to 20% of the selected setting. This results in safer movements and discourages driving in the raised position. The power tilt feature enables the seat unit angle to be adjusted backwards when on a slight downhill slope.

Activate's flexibility in manufacture has led to some interesting projects, of which the most interesting is the Double Power Chair. This was designed for a family with two disabled children, with an attendant control at the rear for the parents to operate. This enabled the family to get out of the house at weekends and during holidays as they no longer needed two people to push wheelchairs.

Activate's range includes many other aids for daily living. The mobility range covers all requirements for postural support on wheelchairs and buggies. The seating systems are used for indoor functional seating, in addition to comfort seating and bathing products.

Activate can be contacted on:
Tel: 01722 340600,
Fax: 01722 414884 or
email: sales@activateforkids.com

Dynamic Seating

Iain McDonald, Theraplay

Successfully seating children and adults with high tone is a difficult task for seating clinicians. The frequency and strength of extensor thrusts can lead to discomfort in the individual, skeletal deformities, pressure issues, and equipment breakdown. These high tone episodes can be a result of sensory input, environmental factors (temperature, noise), primitive postural reactions, postural reflex mechanisms, and general positioning in space.

Traditional rigid style seating constructed from wooden base boards layered with foam and covered with upholstery seeks to contain this extensor spasm. The use of anti-thrust ramps with anterior pelvic positioning straps and knee-blocks seek to reduce the high tone episode and restrict the unwanted movement of the person in the seating unit. Unfortunately, this approach can lead to equipment breakage of foot supports and head supports as the energy generated from the spasm is transferred through the seating unit to the extremities. In these systems, the high tone individual will use the rigid back support as a point of leverage and thrust into the anterior pelvic belt and knee-block if one is being used.

An alternative approach has been pioneered in Sweden by Anatomic SITT who have developed a dynamic system that has been in use for over 10 years. The Dynamic components in the “Flex” units move with the individual. As pressure is applied to the back support, the back support unit will move and allow the individual to extend. Then, as the spasm passes, the seat will return to its original position. By allowing the thrust to happen the person can tolerate the seating position for longer periods of time. In addition, the pressure being applied to foot supports, head supports, anterior pelvic strap, and the seat base is greatly reduced which can help to reduce the likelihood of skeletal deformities and eliminate equipment failure. Other benefits, which have been observed, include improved fine motor skills (greatly beneficial for driving power chairs), better eating and swallowing. Theraplay Ltd is now distributing these Dynamic Seating units throughout the UK.

These seating units are available in two ranges; Delfi for young children through to 12 years and Sharky systems for teenagers to adult. Both are adjustable, allowing room for growth, adjustable degrees of leg abduction, and adjustment for leg length discrepancy. Constructed from a highly durable plastic, the seat units are contoured to match the curves of the human body and are easily adjusted and maintained. An extensive list of additional positioning accessories allows the Delfi and Sharky seat units to be tailored to the individual.

To learn more about the Dynamic Seating from Theraplay call 0141 876 9177 or email: theraplaysales@aol.com

The Future's Bright for the 1107, but it's not Orange

Craig Sweetlove, Product Development Manager, Pride Mobility Products

March saw the introduction of a new Paediatric version of the Quantum 1107 Powerchair from Pride Mobility. This is sure to follow on from the success of the Quantum 1107 in 2006, but why? The answer is simple.

From the floor up, the 1107 is packed with features that make this the ideal paediatric Powerchair. In its more basic forms the chassis is a take-apart machine, making it easy to transport in a car. Mid-wheel drive technology allows the chair to negotiate tight turns, turning in as little as a 19.5 inch radius. Our Quantum motors enable the chair to be controlled much better at low speeds and give greater performance outdoors. 2007 is seeing new colours from toxic green to Barbie pink with a pearl overlay (but not Orange). The Synergy seating is designed to grow with the child, offering up to four inches in width and depth adjustment, and still supplies a stable base for pressure relieving cushions. The seat base can also be adapted for more specialist seating. With the option of a power tilt arriving in the summer, and a manual tilt also available, the Dynamo 1107 is a highly adaptable Powerchair at a cost-effective price.

Tel: 01869 233100

General Features

Reflections of a Grumpy Old Committee Member

David Thornberry, Consultant in Rehabilitation Medicine, Plymouth Disablement Services Centre

I learned today from Olwen of Arthur Taylor's imminent retirement. On behalf of the current committee, Olwen has asked me to record some thoughts about the early years of the Posture & Mobility Group to mark this event.

Arthur and I were both members of a steering group formed to lay the foundations for a society for those with an interest in wheelchairs and special seating. This steering group was hastily assembled at the end of a clinical meeting, which occurred in Salford. This was the last event to be sponsored by the Disablement Services Authorities. From memory there was a much more heated discussion about what the group should call itself than who should be elected to represent it! A steering committee was formed, and planned a meeting for the following year in Swansea. Apart from a national rail strike on the day, and indifferent wheelchair access to the main lecture theatre, the Swansea Conference was a success and a definitive committee was elected by the membership, which agreed to call itself the Posture & Mobility Group. Both Arthur and I survived the transition from the Steering Group to the definitive committee.

Looking through the rose tinted retrospectoscope, and considering what the group has achieved and continues to achieve, it is easy to contemplate the past with a smug self-satisfied glow. The truth of the matter is that the PMG Committee, although undoubtedly willing, was on a very steep learning curve. The committee membership had a good balance of members from different professional backgrounds, including from the NHS and private industry. It has been the strength of the group over the years that this balance has been fairly well maintained. The problems facing PMG in the early years were quite different from those which the committee encounters today and were arguably more fundamental: we had no money, we had to acquire a paying membership, but the subscription could not be too great so as to discourage the poorer-paid members. This was where we made our first big mistake: that was to offer both private and 'corporate' membership. The idea was to allow Health Establishments or private firms to sign on several of their employees as a group. The nightmare of policing this and keeping track of personnel, who rapidly changed employment, fell to the Membership Secretary, who also happened to be the Treasurer. Advice to anyone thinking of starting a new organisation: have personal membership only, paid by annual direct debit on the same date each year.

Without the safety net of the Disablement Services Authority, our biggest concern was of having a conference which flopped in terms of the number of attendees, which could bankrupt the PMG before we had even started. The secret of financial success of conferences is to provide an all-singing, all-dancing commercial exhibition. Starting off, we had not had one of those. The other important thing we did not have, starting off, was a secretariat. The committee did not have the skills nor the time to spend on the 'nuts and bolts' organisation necessary to run a conference. There were lots of good ideas about speakers and committee members willing to pull in favours to establish an interesting programme.

In order to protect against the risk of failure and to tap into the conference organising facility, we entered into negotiation with the Bio-Engineering Unit at King's College Hospital. These negotiations were somewhat sticky and the service was expensive.

In the early years of the group, we had two out of three of the first conferences at Warwick University. Their facilities must have improved somewhat since then, because the maximum capacity of the theatre we booked then was only 270 people. The break-even number of delegates was just over 200 and we were worried that this might not be achieved. In the event, we had over 260, a good commercial exhibition and the conference was a scientific and commercial success.

We had an early meeting at Nottingham University before the East Midlands Conference Centre was as accommodating as it is now: there was plenty of room for delegates but not for a commercial exhibition. We learned our lesson from this, as the Group made very little money and this delayed our being able to sever our ties with the King's secretariat by a year. After three years we had a sufficient float in the account to risk 'going it alone' in terms of conference organisation and could shop around for a cheaper service. This was helped by holding a couple of meetings in Wales, where the Welsh Tourist Board are particularly generous if you promise them 300 visitors for a couple of days in the Principality. You do though need to be respectful of the culture. On one occasion, for example, it was suggested that a male voice choir singing in the gallery during the conference dinner might be appropriate, but this could only be allowed if everyone stopped eating.

Fairly early on there was a conference on Arthur's home turf of Llandudno. The committee had a meeting the night before. Our entertainments secretary had booked tickets for all at the theatre in Llandudno. We knew that this theatre is the northern base for the Welsh National Opera and were naturally anticipating an evening of high culture. To the dismay of some and to the delight of many more of us, we were treated to an evening with Joe Pasquale!

The early committee meetings were established at King's College on the Strand in London. Arthur probably had the furthest distance to travel to the meetings, although others had to come from as far away as Scarborough and Plymouth. The meeting room had a delightful aspect looking across the river beyond Temple Station towards the South Bank. We were able to observe the construction of the London Eye and I have since gazed down from one of the pods to the back of the King's building.

The meetings were not too intense. The business was by and large addressed and got through. There was occasional robust discussion, usually relating to conference dinner menus and the wine list! In those early years, the foundation for successful conferences was laid, largely by learning from our mistakes. The Health Service at the time was in the post-Thatcher era of the internal market, and an early achievement was to publish a guide to prospective purchasers of wheelchair and seating contracts.

The PMG newsletter was launched, although at that time it looked more like a political pamphlet than the glossy periodical which we now enjoy. The foundations for a large international event were laid, and culminated in our collaboration with the Scottish Seating & Wheelchair Group at the Dundee '97 International Conference.

The committee meetings usually terminated in time for the distant travellers to catch the train home. On one occasion I was spotted by the (then) Chief Executive of our Trust at the bar of the Great Western Hotel in Paddington, late one Tuesday afternoon, with a pint of Guinness and a cigar (those were the days!). “I have been to the committee meeting of the newly formed Posture & Mobility Group for England and Wales”, I announced proudly. “Never heard of it,” she snapped. Further conversation was mercifully curtailed as we went to catch our train, and she boarded the first class dining compartment.

It is reassuring now that PMG has no particular financial concerns and indeed is able to feedback to the membership by way of bursaries, book schemes etc. The worry that venues are now not large enough to accommodate all delegates at a PMG Conference is a worry, but one which is nice to have. The development of the sub-committee structure; the continued professionalism of the newsletter; the continuing links with the Scottish Posture & Mobility Network and other international organisations is further testament to the evolution of the group.

I should like to take this opportunity to pay tribute to all the early committee members, some, such as Roy Nelham and Patsy Aldersea, who have now retired. Many others have not, and they continue to play an active role in the development of the PMG. The annual conference, or the “National Training Event”, allows many of us – now undoubtedly grumpy old men and women – to get together again as “pioneers reunited”.

And Arthur: he has been Consultant Clinical Engineer and Head of Rehabilitation Engineering Services for North Wales for over 15 years. He was instrumental in setting up the Rehabilitation Engineering Unit based at Bryn-y-Neuadd Hospital in 1984. Further workshops and clinics were set up in Wrexham and at Newtown in 1987 and 1991 respectively.

On behalf of PMG, I wish him and his family a long, happy and active retirement.

Musical Chairs

Martin Moore, Wheelchair Project Manager, JCM Seating Solutions Ltd www.jcmseating.co.uk

As I sat and reflected upon my personal experiences with four companies in the rehabilitation equipment and seating industry it became more obvious that 22 years was, paradoxically, both a very long and a very short period of time.

A lot has changed in the industry that I joined, as well as around and about it. To me it appears as though these changes have simply followed the more general patterns of change in our society and in our world over the same time. There is less time, more expense, larger barriers; and still as much, if not more, need for products. Paediatric seating, and equipment itself generally, has stood still in my opinion, although on the surface there appears to have been radical improvement.

Not all the changes in the industry, in my opinion, have made it any better either.

When I first set out on my path – some might call it a career path, but I prefer to think of it as ‘The long and winding road’ – the vast majority of companies making equipment fell broadly into two categories. Alongside these private organisations stood the public sector industry spread throughout the NHS, who essentially provided an orthotic and prosthetic service and specialist equipment provision in some areas mainly allied to the old structures of the ALACs.

In the private industry sector the companies were either well-intentioned, small, family-owned businesses, or they were established businesses in or on the periphery of the industry supplying the NHS itself. The small enterprises were often set up because a relative decided to use their skills for making a ‘one off’ aid to help someone with a disability in the family to have a better life, finding later that other people would like the same thing too.

This probably could not have happened so easily were it not for the industrial fallout of engineers, technicians, craftsmen, and skilled people from the dying British economy of the 70s and 80s being available. They were glad to find work, and happy to find a worthwhile place to exercise their creative talents. Alongside this were a growing number of college and university leavers who would have been drawn into the industrial economy before, but faced the same challenges in finding useful employment. What they lacked in knowledge of disability was amply made up by enthusiasm for the work and a thirst for learning more.

An industry had been born and was now toddling. There were many grateful consumers of their wares. Where previously families struggled to cope with daily activities, equipment was there to offer life with improved comfort and hope for an easier future

But, in a typically British way, it was not long before the enthusiasm and transfer of skills into the growing healthcare market was to meet some form of barrier to unbridled freedom. This came in the form of heightened attention from the bureaucrats and academics wanting to quantify, label, measure, and qualify all things. After all, there were a lot of other people displaced by the industrial meltdown of the times, and they had to find work as well!

A lot of pressure came from changes starting in the NHS, affecting contractors’ work with them; but the EU also started to have wide-ranging affects on all kinds of product and service provisions. To be fair, this happens in many private sectors: self regulate or be regulated. Government funding requires the best, often for the least or close to it, and is surrounded by checks and balances that can stifle the creative individual.

Compare this with the industry of today. A much bigger industry with a mix of small to huge multi-national companies supplying a vast range of goods and services, vying for a slice of the massive and growing healthcare markets in a profit-led environment. Where fledgling and amateur companies once were, there is now a hardened and hungry machine looking for the next opportunity to move forwards or just survive.

Where the services existed, within the leaner and meaner NHS there have been equally as many challenges in performance and practice to respond to; but, in the main, services have been eroded away and the effect on seating services in particular has been dramatic, with a lot of provision now contracted out to the several large private companies operating in the field.

But who will survive and who will fail now? Is there enough room for those well-intentioned and passionate individuals still left in the industry? What about the providers in the NHS?

It is maybe not surprising that when you look at today's industry there are many multinational companies creeping into every service sector where there are tenders available. Yes, amongst them are also some of the original start up companies and individuals that have weathered the storm and been able to adapt to keep themselves ahead of the tide of change and competition or fill a niche position.

But where has this left the child in need of seating and equipment, and their and their family's needs? Equipment for children in general used to be relatively simple, basic, functional, and relatively reasonable in cost. It answered their basic needs. It appears now to be complex, multi-functional, superior, but not so reasonable in cost or even verging on the expensive. Why is that?

The most significant factor in this process has been the move to a society where the individual is placed centrally. Risk averse or indeed risk paranoid policies and protocols exist. Apparent growing wealth feeds the drive for higher expectations, and technology has made all but hand-crafted and labour-intensive products much cheaper.

The seats and equipment of today, be they modular, hybrid, or custom, have to solve more problems – due to the nature of the carers' interaction with it and regulatory needs – than ever before. The needs of the disabled child have changed a little over time, indeed, but not so much as the demands of those around them. Manufacturing methods have remained little changed either. Therefore the needs of the child are interpreted and become diminished by the needs of those around them and society as a whole, and, although often talked about as being paramount, are in fact secondary.

We have less time to spare, are more stressed, less willing to take on compromises in our lives, want to do less physical work, do not want to put ourselves out and expect the very, very best of everyone else. A cynical view perhaps, but one I am sure you recognise.

Where costs are required to be driven down then there is a fine line to be drawn between value, specification, and performance delivery, but in general companies looking for profit opportunity know that these factors are seldom really measured at all, because the playing field is not level and comparison is hard. Well written contracts look great, but are the terms ever checked out for real by those who write and understand the dynamics of the clauses?

Comparison between private companies and public services is difficult too, as the dynamics of business do not as yet fully operate in the public sector. The consequence is often that the best value cannot be ascertained, so often budgets are spent more quickly than they might be on products of less worth.

So, where are the craftsmen and women coming from for tomorrow's generation of positional seating and equipment? Are we training anyone to do this? Will the specialities survive or will we get it all out of a box? Where is the research, and can ethics committees allow us to do any, anyway?

There can be no doubt that children's equipment looks more sophisticated now and has a higher material specification than before and is better designed and produced in general terms. It certainly ticks more boxes for the children's and their carers' needs as we are presented with them in today's world. But a lateral pad is still a lateral pad, a head support still a head support, and a seat still fits in the same place as it ever did. There may be a greater choice of colours, but fundamentally does the seat work anatomically any better or control the child well?

It is generally lighter in weight, might look better and appear more user-friendly. Technology has opened up many areas that were inaccessible before, such as in communication, general mobility, and access to compact life support equipment, that allows improved social inclusion for those needing this equipment.

Socially there have been huge strides forward in inclusive treatment and recognition of and intolerance to discrimination in all its aspects. The manufacturers and professional support staff are better informed and trained, more aware of potential areas of risk and poor practices, and involved in general in the wider society of care through organisations such as the PMG and SPMN.

But children spend more time in the equipment, it's more complex to set up and adjust, it needs more maintenance, and most people are frightened to even pick up the thick instruction booklet in case the pages and pages of "Do's and Don't's" give them nightmares, or they are put off using the equipment because they are worried they won't remember it all.

Costs rise because more hurdles are placed in the way and there is a greater and ever more complex list of wants and needs, some of which are at times conflicting.

So, in conclusion, I have to warn everyone that we have to take some care, otherwise this may end up just like a game of MUSICAL CHAIRS. The music starts, we all run around the same floor again and again until some one turns the music off for a short while and we try to find a seat, but the resources have reduced a little more yet again, or the goals have moved somewhere else.

The colleagues and principles we lose in this game might just have had the answer to the problem we were trying to solve, or were they just too slow or out-of-fashion? What appears to be good value might be poor value and lead to someone's position or business becoming impossible to sustain and so there is less competition, not more. An old theory might not hold water in light of new thinking.

The industry has more people doing the same thing for the same group of people than it did 22 years ago. However, it is market led, not research and needs led and I see little basic difference in the chairs of yesterday for children. The basics are still the same and we must get that right and not allow ourselves to be diverted by trends and fashion. Few are looking at first principles and individual needs.

And it seems such a little while to have been watching and participating in all this action. The time has flown past at an alarming speed; but – as I said in my opening lines – paradoxically it has been such a short time in the life of an industry which has only been growing for around 40 or 50 years worldwide and is therefore relatively new. Perhaps the rest of my 'Long and winding road' will have equally interesting and thought-provoking times in store as well.

Kneeblock Research at Oxford Brookes University

Guy Barton, Research Physiotherapist (Oxford)

Kneeblocks have been a feature of some special seating systems for many years now, and the debate over their efficacy has raged for just as long, with often entrenched opinions on both sides of that debate. Unfortunately there has been no empirical evidence produced to date to weigh the argument in either direction, and clinicians have had to use their experience and intuition to make prescriptions. In an effort to produce evidence to sway the debate and remove some of the guess work, Dr David Porter and his team at Oxford Brookes University are undertaking a three year randomised control trial of kneeblock use in special seating for children with Cerebral Palsy and related conditions.

The trial will examine the effect of kneeblock use on hip migration percentage, a commonly used measure in determining the need for re-constructive hip surgery in this population. Other measures being examined through the study will be any effect on pain – via the Paediatric Pain Profile, levels of lying and sitting ability as measured by the Chailey Levels, and a simple test of upper limb/trunk ability. Subjects for this study will be recruited at the start of the study from a population of children aged between 2 and 12 years with Cerebral Palsy or related, non progressive/ degenerative condition. A gross motor score of 4 or 5, as measured on the Gross Motor Function Classification Scheme (GMFCS), and a need for seated postural support are also prerequisites.

Once children are recruited onto the trial they are provided with a seating system from one of two major suppliers supporting the research, and then randomised into the intervention (with kneeblock) or control group. Children in the control group can be supplied with a pommel for adduction control. This seat is fitted to a wheeled base supplied by their local wheelchair service, and maintained throughout the period of the study by the project researchers.

The study currently has ethical approval in Oxfordshire and Yorkshire and is running in those areas; however, due to the need for a large cohort of subjects to make the analysis more valid, further subjects are being sought in other areas. If you work with children in this client population and can recommend subjects for the study, please contact:

Guy Barton, Tel: 01865 482711 (Oxford)
Lynley Page, Research Physiotherapist (Yorkshire), Tel: 07794 750933, or
David Porter, Principal Investigator (Oxford), Tel: 01865 482667

If there are sufficient numbers in an area, ethical approval can then be sought to expand the study.

Paper on Self Care in Assistive Technology from the Foundation for Assistive Technology (FAST)

Summary by Helen Hislop, Haringey Wheelchair Service, PMG Communications sub-committee

The purpose of this paper is to set out the current position of self care in assistive technology (AT) and to stimulate debate across service users, government departments, service commissioners and practitioners, social care and education on how to implement a self care approach to AT in the future.

The report outlines the case for developing self care strategies and the risks inherent in these for users. The report also runs through key issues for self care in relation to current provision, including awareness/information, assessment, decision making, financing, and sustaining the use of AT.

Three potential models to support self care in AT are examined, and the aims, related strategies and outcomes of all three are discussed.

To read the document in full and comment on the proposals made, contact:
Keren Down at FAST Tel: 020 7253 3303
email: info@fastuk.org Website: www.fastuk.org

Getting Flammability into Perspective

Barend ter Haar, Task Group Leader, ISO TC173 WG11 Working Group on Flammability
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Within the realms of posture and mobility, wheelchair cushions in the UK have been dictated to for a number of decades by furnishing fire standards. This is at last set to change with new work on flammability standards for wheelchairs and their attachments, to take them away from the furnishing domain and back into the needs of medical devices.

Mattresses and furnishings became covered in the ’60s and ’70s by new standards of flammability testing after some horrifying disasters where institutions, dance halls, and other public places burned down as a result of the inflammatory properties of the furnishings, with accompanying injuries and fatalities. The regulatory response was to develop a series of flammability test requirements in the UK, which included tests up to the Crib 5 test where a ‘crib’ of wood burned for 5 minutes on the furnishings and the material had to ‘survive’ this test. The UK still has some of the most stringent furnishing fire regulations in the world to this day.

NHS requirements

The NHS issued requirements that furnishings including pressure care equipment supplied to hospitals pass the Crib 5 test. As a result, many NHS purchasing officers included this requirement for all purchases, whether for hospital or other use. Whether this standard was relevant to wheelchair cushions or not, it was still applied to them, since there were no standards available to cover cushions as separate products. Along the line, within the wheelchair standards, ISO 7176 part 16 was published in 1977 to cover the upholstered parts of wheelchairs. However, this again was based on upholstery flammability standards, where the key test was to apply a flame source at the junction between a horizontal and a vertical surface, which you might typically find between the seat and the back. However, with someone seated in a wheelchair, what are the odds of a source of fire getting there?

The approach to the new standards is to look at the risks. What are the risks to the wheelchair user from the chair, the cushions, and the materials they are made of, and how great is the risk of fire as compared with other challenges to the health of the user? The statistics indicate that over the years there have been very few instances where wheelchair users have been affected by fire in their wheelchairs where the cushion has been implicated. The greatest risk has come from people wearing inflammable clothing which has caught light from being too close to a fire or other heat source.

On the other hand, the greatest threats to the health of wheelchair users have come from inadequate seating and cushions not preventing tissue breakdown, or inappropriate positioning leading to scoliosis or contributing to increased kyphosis. Fire retardancy requirements may have kept back from the market, and thus the wheelchair user, various materials which might have provided better maintenance of tissue integrity.

Flammability standards in perspective

It looks, though, as if sanity may be descending on the wheelchair and pressure care cushion environment. Working one's way around the wheelchair we find components which have increasing importance with respect to tissue integrity of the user.

A potential area of major ignition sources are the electrical components found on a powered wheelchair or one that has battery powered components. Wheelchair standards within the 7176 series (e.g. Part 14) provide protection by requiring that potential electrical/electronic ignition sources be surrounded within fireproof enclosures.

At the next level, a new standard is proposed within the 7176 series where the structural components of the wheelchair should provide a reasonable fire barrier to protect the individual. Thus, for example, if a wheelchair is positioned near a fire, the components, whether composite, plastic, or wood, for example, will not start to smoulder or catch light.

The existing standard, ISO 7176 part 16 covering the upholstered parts of a wheelchair (such as arm supports) has been reworked and is now being passed around the international community for voting. The key components of the current proposal are that this covers any upholstered components that are fixed to the wheelchair and require a tool for removal (if they are not upholstered they will be covered by the new standard described in the previous paragraph). This will embrace items such as padded belts and harnesses, and padded canvasses.

The fire source has been restricted to Ignition source 1, which is a match equivalent. The risk balance applied is that these components have a mix of structural contribution and the possibility of affecting tissue integrity. They are also exposed to some degree to smokers' materials and other lit items falling on the wheelchair.

Finally we come to the items that provide the highest clinical importance. These are the removable cushions and backs in the chair. These will have been specifically prescribed items relating to the clinical needs of the wheelchair user with respect to their tissue integrity, function from the wheelchair, and/or positioning needs. On the other hand, the risk of an ignition source getting close to them is much less since they will be covered by the user while in their chair. The greatest fire source risk could be a cigarette dropped at the exposed edges, and therefore it is proposed that these items are tested to Ignition source 0, a so-called smouldering cigarette. Work is being carried out at present to design a reproducible heat source that behaves like a smouldering cigarette, but that is more reproducible than using cigarettes randomly out of a packet.

Thus the more clinically important the component on the wheelchair, the less responsibility it has as a fire barrier, and the greater the responsibility for its clinical function.

Further considerations

Not yet covered by the wheelchair and cushion standards is the challenge of poisonous materials potentially released during combustion. The new standards request that manufacturers aim to choose materials with the least risk of releasing noxious materials, but more research is probably needed before this can be regulated for. However, in the aircraft industry, plane seat requirements have become more stringent, and the posture and mobility world may benefit from new materials from another industry.

Another area that needs greater awareness is that increasing numbers of wheelchair users are having complementary therapies which can increase the fire risk. Not least of these is the use of oxygen therapy which can turn a relatively inert material into a highly inflammable product. Manufacturers at least have a responsibility to warn their customers of this.

The further area for duty of care is around the changes of flammability properties arising from washing, time, and ageing processes. There is another cushion seating standard in preparation which is designed to look at the changes of a cushion's physical characteristics with ageing, using accelerated ageing techniques. It is expected that the effects of ageing on flammability will be taken into account.

In conclusion

Flammability standards around clinical products are progressing, to take into account the clinical needs of the individual and placing these needs in perspective with the flammability risks. This progress has already occurred with incubators for neonates. The progress is now appearing for cushions and wheelchairs. We must try to work with procurement agencies, and regulatory bodies, and show them that tissue integrity and mobility positioning products are not commodities that can be treated as being identical, but each individually provides for specialised, clinically prescribed purposes. The clinical risks have to be balanced with other risks, including those of flammability.

RESNA Position Paper on the Application of Wheelchair Standing Devices

Nigel Shapcott, Head of Rehab Engineering, Morriston Hospital, Swansea, Member of PMG Committee

The Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) has produced its position paper on the justification for standing wheelchairs for the USA and Canada. In these countries insurance companies pay for wheelchairs and other health care needs. The insurance companies follow Government coverage policies (Medicare/Medicaid) which are constantly under review. RESNA has a long history of consultation with Government over Assistive Technology issues in order to improve services to individuals with disabilities and this is a tangible example which translates very easily to the UK situation.

My feeling is that this gives PMG a very clear template for medical justification for a range of features on wheelchairs which are currently not made available through the NHS. The position paper also points out where such devices have other benefits, for example in independent living, which may then form the basis for policy changes which may allow joint funding to be sought.

The RESNA Position Paper is available to download from the PMG website:
www.pmguk.co.uk/Home/Publications

Additional material about standing wheelchairs in the UK can be found in the article "Standing isn't a Luxury" by Anne Harris and Joanne McConnell in Volume 22 of the PMG Publication (Spring 2006). This issue can now be downloaded from the PMG website:
www.pmguk.co.uk/Home/Publications/Newsletters

Work Experience Request from Italy

Chiara Pasqualetti, Associazione La Nostra Famiglia

I'm Chiara, an Italian physiotherapist, and member of PMG. I am writing to my fellow members to ask for advice. I work in Italy in an AT consultant service, where there is an opportunity for me to deal everyday with wheelchair and posture management, environmental adaptation, orthosis, evaluation of driving skills and driving adaptation; also augmentative and alternative communication in children up to the elderly; many disabilities like multiple sclerosis, cerebral palsy, Parkinson's disease, post-traumatic brain injury disease.

I have joined PMG hoping to gain more knowledge and input about wheelchair and posture management, especially in severe cerebral palsy and severe traumatic brain injury. I am also very interested in car seating adaptation which is not so personalized and common here in Italy.

I have written this piece in the hope that one or more of you may be able to offer me the chance to improve my working experience with a practice period, by visiting your centre or service involved in the same field.

Thank you all; hoping to hear from you.

Best regards,

Chiara
chiara.pasqualetti@tele2.it

POSTURE & MOBILITY GROUP

1st Announcement and Call for Papers

National Training Event 2008

Warwick University

10th & 11th April 2008

Papers (for platform and/or poster)

Contributions are invited from the PMG membership and all professionals working in the rehabilitation, posture and mobility fields.

Full details of the format required for abstracts and the submission form itself can be found on the PMG website (www.pmguk.co.uk). Abstracts should be submitted online via the website; however if you do not have access to the internet please contact the conference organiser.

Abstract submissions open on PMG website (www.pmguk.co.uk) from 1st September 2007.

Best Free Paper: £100 Best Poster: £100

Bursaries

The Posture & Mobility Group will again be offering a limited number of funded places at the event. This is an opportunity for PMG members working in the wheelchair and special seating service, or those who have a particular interest in this specialist field, to apply for a funded place.

As a condition of receiving the award, a bursar agrees to write a report about one of the 2008 PMG National Training Event plenary or parallel sessions they attend.

Bursary applications open on the PMG website (www.pmguk.co.uk) 1st September, 2007.

Posture and Mobility Group NTE,
PO Box 776, Taunton, Somerset, TA1 9BR
Tel: +44 (0) 1823 252690 / +44 (0) 845 1301 764
Fax: +44 (0) 392 490634
Email: patricia.marks@pmguk.co.uk

www.pmguk.co.uk

Increased Productivity in Turnround of Wheelchairs

Barend ter Haar, Director, BES Rehab Ltd, Email: barend@besbiz.eu.com

Dundee's Ninewells Hospital houses one of the five Scottish wheelchair services, at the TORT Centre. When the service was moved from its base in Broughty Ferry onto the Ninewells site a few years ago, they brought with them all of their in-house bespoke manufacturing and repair abilities. This included a pressure washer used outdoors to clean wheelchairs as part of the refurbishment process.

Geoff Bardsley, recognising the risks to his staff and the unproductive time involved in cleaning equipment before it was refurbished for the next client, applied for funds to automate the washing of chairs when they were returned from clients for repair or recycling to new clients.

At last, in December 2006, he had installation and commissioning of his AquaPhase 3000 medical equipment washer completed. The result has been a 50% increase in the rate of refurbished wheelchairs from the workshop within the first 6 weeks.

The journey to this point had not been without interest. A room to house the AquaPhase needed to be built onto the end of the workshop area, with its own loading and unloading platform. Delays arose as the footings were dug out to find the foundations for the building higher up the slope stretched across the proposed area for the room. Next, the building drawings ended up with the internal measurements being used as the external dimensions for the initial building work. Other interesting variations to the original plans materialised. However, 9 months later than anticipated, the room was ready, and the staff are delighted with the time saving and improved cleaning that the AquaPhase now offers. If also avoids refurbishment staff having to carry out an unpleasant task outdoors in all weathers.

Linsay Stevenson, the Scottish Manager of BES Rehab, the supplier of the AquaPhase, adds: "Washing and disinfecting medical equipment such as wheelchairs in an automated washer protects the workforce from the risk of catching an infection such as Hepatitis from the equipment: no-one can tell which piece of equipment carries such a risk, and therefore each piece needs to be rated as being infected. Pressure washers create a potentially contaminated aerosol which can be breathed in by staff and people casually walking by, whereas an enclosed automated cleaner contains the risk.

In addition, automated cleaners get into nooks and crannies which are difficult to reach manually, while also allowing the operators more time to get on with more valuable work, such as repairs. One of our customers in the Midlands calculated that their AQ3000 saved them over £40,000 in its first year of use.

In Scotland, the wheelchair services in Aberdeen and Glasgow now have AquaPhase units, as well as most of the Community Loan Stores; BES Rehab has installed over 100 of the AQ3000 and its bed-sized companion the SaniPhase AQ4000 across the UK."

BES Rehab Ltd
M2 East Way, Dales Manor Business Park,
SAWSTON, Cambridge CB22 3TJ
Tel 0845 1300237 Intl +44 1223 839500
Fax 0845 1300238 Intl +44 1223 839237

THE POSTURE AND MOBILITY GROUP

DETAILED STATEMENT OF FINANCIAL ACTIVITIES

YEARS ENDED 31 DECEMBER 2005 and 2006

		2005		2006
	£	£	£	£
INCOME				
Subscriptions		**9,052**		**9,847**
Bank interest		**4,813**		**4,504**
Courses		–		–
Conference and exhibition		**38,642**		**143,164**
Advertising in Bulletin		**170**		**1,000**
Other income		–		**1,163**
TOTAL INCOME		**52,677**		**159,678**
CHARITABLE EXPENDITURE:				
Conference and exhibition expenses			**81,652**	
Course expenses	**229**		–	
Books subsidy	**6,365**		**5,427**	
Research and development projects			**7,842**	
		6,594		**94,921**
MANAGEMENT AND ADMINISTRATION				
Administration	**14,330**		**20,058**	
Website development	–		**6,087**	
Newsletter	**16,482**		**9,802**	
Office	**425**		**710**	
Accountancy fees	**815**		**150**	
Committee expenses	**8,007**		**8,800**	
Bank charges	**1,967**		**429**	
Other expenses	–		**161**	
Depreciation of fixed assets	**784**		**784**	
		42,810		**46,981**
TOTAL EXPENDITURE		**49,404**		**141,902**
NET INCOMING RESOURCES FOR THE YEAR		**3,273**		**17,776**

THE STATUTORY ACCOUNTS OF THE POSTURE AND MOBILITY GROUP ARE POSTED ON THE PMG WEBSITE WWW.PMGUK.CO.UK HARD COPIES OF THE STATUTORY ACCOUNTS MAY BE OBTAINED FROM THE SECRETARIAT.

THE POSTURE AND MOBILITY GROUP

BALANCE SHEET

YEARS ENDED 31 DECEMBER 2005 and 2006

Please view PMG website www.pmguk.co.uk for full statutory accounts or contact the Secretariat for a hard copy	**Total Funds 2005 £**	Total Funds 2006 £
FIXED ASSETS		
Tangible assets	**2,353**	**1,569**
CURRENT ASSETS		
Debtors	**4,253**	**32,064**
Cash at bank	**240,615**	**169,556**
	244,868	**201,620**
CREDITORS: Amounts falling due within one year	**(103,479)**	**(41,671)**
NET CURRENT ASSETS	**141,389**	**159,949**
TOTAL ASSETS LESS CURRENT LIABILITIES	**143,742**	**161,518**
NET ASSETS	**143,742**	**161,518**
FUNDS		
Unrestricted income funds	**143,742**	**161,518**
TOTAL FUNDS	**143,742**	**161,518**

These financial statements were approved by the members of the committee on the 13th March 2007 and are signed on their behalf by:

Mr Henry Lumley

14 March 2007

PMG Education & Training Sub-committee

Report from the chair, Martin Moore

As most of you will be aware we have our first sub-committee training course running in May. Jill Monger is a really exciting speaker and trainer and we are delighted that she has agreed to come over from America to run two one-day courses in Birmingham. The price of £40 is very good value and has been achieved mainly due to Whizz-Kidz kindly offering their facility in Birmingham free of charge. A big "Thank You" to Whizz-Kidz for this.

Work is continuing on compiling a list of courses and providers of courses available in the posture and mobility field. This is taking some time to create, but we will be making it available on the PMG website as a resource to the members. Watch this space for news of its launch.

I hope those of you booked onto the course in May enjoy it and get some good CPD from it. If there are any subjects you really want covered by 1 or 2-day courses, please contact us and we will try to find speakers to run a course. If you know of any good speakers or have material you would like to share, again just let us know. Who knows, you could be our next course speaker!

We are also always on the look-out for suitable venues to host PMG courses in various regions of England & Wales. Requirements for a course venue are:
Good rail & road links
Large room (minimum 40 delegates)
Disabled access/facilities
Basic kitchen facilities
Parking
Local member to liaise with PMG and to support the day.

If you would like to have a course in your region and can tick all the above, please contact PMG Administration, **email: olwen.ellis@pmguk.co.uk**

PMG Research & Development Sub-committee

Report from the chair, David Porter

Over the last two years the R&D sub-committee has concentrated on launching and running the new PMG research funding scheme. This scheme is intended to fund salary replacement costs for PMG members in order to allow them to conduct a small-scale research project. Further information on the scheme is available on the PMG website (www.pmguk.co.uk/research).

In the first two rounds funding was offered for five studies on a diverse range of topics:

- Wheelchair mobility for people following stroke with perceptual problems. Dr David Punt.
- Balancing manual wheelchair stability and 'tippiness' for functional independence. Lynne Hills.
- Is static interface pressure mapping reliable for ranking pressure-relieving cushions for active (dynamic) wheelchair users? James Hollington.
- A study of the biomechanics and kinematics of standing during development and in children with cerebral palsy. A three-phase study. Alice Wintergold.
- A single blind controlled study to assess advantages of Pushrim Activated Power Assisted Wheelchairs. David Harrison.

The first two projects carried out by David Punt and Lynne Hills are nearing completion and findings will be presented at the PMG National Training Event and in the PMG newsletter. James Hollington managed to carry out his study before leaving Enable Ireland without taking up the offer of PMG funding and his work will also be presented at the NTE. Alice Wintergold's study is on hold while she is on maternity leave and funding has recently been awarded to David Harrison for his study.

Outline proposals are currently being invited (closing date 30th April 2007) and there will be another call for proposals during the summer with a deadline of the end of August 2007. So if you are interested in taking some time out from your normal working week in order to carry out research that will contribute to the evidence base, then why not submit an outline of your proposed study.

I am very grateful to all the members of the R&D sub-committee, and also the people who have kindly carried out peer reviews, for committing their time and effort to allow this scheme to happen. Thanks also to Olwen Ellis for her very efficient administrative support.

The sub-committee currently consists of three elected members of the PMG committee plus five other people with an interest in research.

PMG R&D Sub-Committee
David Porter (Chair), Oxford Brookes University
Donna Cowan, Chailey Heritage Clinical Services
Alison Johnston, Bromley Wheelchair Service
Sally Kyle, Waltham Forest Wheelchair and Special Seating Service
Steven Mark Guy Rolfe, Industrial Designer and Wheelchair User
Lone Rose, Stoke Mandeville Hospital
Nigel Shapcott, Morriston Hospital, Swansea
Helen Yarrow, Carer of young service user.

When is a Pressure Ulcer not a Pressure Ulcer?

Barend ter Haar, PMG Communications Sub-committee

At this March's International Seating Symposium conference in Orlando David Brienza, from the University of Pittsburgh, provided an update on current thinking around what pressure ulcers are and what causes them.

First, the staging definitions have been updated, with the new definitions viewable on www.npuap.org. Stage I still has nonblanchable redness as its definition. It is Stage II that has been updated, to partial thickness, loss of dermis, and pink wound bed *without slough*. The word 'skin' as being affected by pressure has been removed, and this has been replaced by *underlying tissue*. This has major implications which will be discussed later.

When is a pressure ulcer not a pressure ulcer?

A new term has been floated, namely Suspected Deep Tissue Injury. Included in the definition is 'Purple or maroon localised area of discoloured intact skin or blood-filled blister due to damage of underlying soft tissue from pressure and/or shear. This area may be preceded by painful, firm, mushy, boggy, warmer, or cooler areas as compared with surrounding tissue'.

One big question that has been debated recently is: 'Are Superficial (Stage I and II) pressure ulcers caused by pressure?' In reality, a variety of skin lesions are caused by elements other than pressure, such as by faecal or urinary incontinence, or excessive sweating leading to skin maceration. Damage can be caused by friction as an individual is moved. Shear may cause stretching and tearing of blood vessels giving nonblanchable erythema over a bony prominence. None of these ulcers should be called pressure ulcers since their primary cause has not been pressure. Hence the changes in the definition of Stage II ulcers described above. These ulcers may be caused by pressure and/or shear and/or friction and/or maceration.

What has research shown?

Bioengineers use the term 'stress' to refer to the effects of pressure on tissues, and 'strain' as the resultant deformation. It is the latter which causes the pressure ulcer. In 1978 Chow & Odell, using a 'linear finite elemental modelling' technique, showed that the strain occurred below the skin surface, and this was confirmed by Todd in 1994 with MRI scanning. Linder-Ganz is shortly publishing a report in the Journal of Biomechanics of a seated person showing that the 'strain' is occurring at depth, while the 'stress' is more widely spread below the skin's surface.

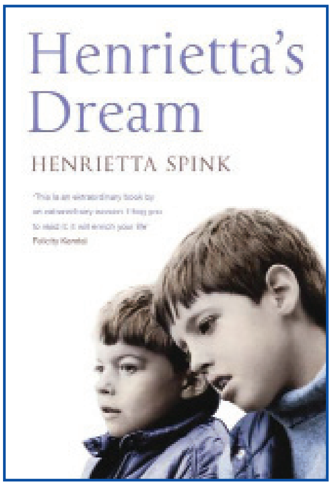
Oomen's work in 2003 showed that the materials affected by strain were the muscle layer near bone, and the fat between the bone and skin. In contrast, cushions appear only to relieve surface pressure, but not deep tissue stress.

The result of this work and the related current thinking is that the techniques such as pressure mapping, which we have been using clinically to prescribe seating materials to reduce pressure ulcers, have probably had limited effect on deep tissue pressure ulcers, and this is maybe why we have not been reducing significantly the incidence of pressure ulcers over the years! Pressure mapping does have its value in measuring the effects of position on likely deep tissue stress and strain, but this does require experienced interpretation of the pressure maps presented. However, assessment techniques which can look at combinations of pressure, shear, moisture, and temperature, will have more impact on prescribing appropriate materials to reduce Stage I and II ulcers.

[If you are looking for a system where the one interface module can be used to map pressure, shear, heat, or moisture, the FSA (Force Sensitive Applications) system can offer all four modalities.]

Reference: Brienza, D 2007 Pressure Ulcers: More questions than answers Abstracts of 23rd International Seating Symposium, p49.

A Summer Read



Henrietta's Dream
HENRIETTA SPINK

I would like to share with you my recent read, ***Henrietta's Dream***, by Henrietta Spink. I was lent this book by a friend who, knowing I worked with disabled children, said: "I've just read this very moving book about two disabled brothers – it's right up your street, I'll lend it to you."

When I was handed the book a few days later I groaned inside, but of course smiled and thanked the friend, while thinking to myself "keep it a week or two, pretend I've read it, then hand it back." To me the book looked like a busman's holiday of a read: no way did I want to spend my precious leisure time reading about the type of children and families I work with each day.

I won't tell you too much about the book as I hope maybe one or two of you might read it this summer. All I will say is that it gives a glimpse over the other side of the fence, to the side of the fence where the families we see are sitting; the side where everything, not just the wheelchair, is a constant fight. It made me think about how I treat the families I come across. I hope I have never said such things as "your child will never do anything for himself". Some of the detail about medical appointments Henrietta had to make for the boys rang too true of some reviews I have sat in on, with a school nurse and paediatrician, when I worked in a large special school.

This is the true story of a very brave and determined mother of two physically disabled sons. Despite being told her sons will never be able to do anything, she won't take no for an answer. She contacts doctors all over the world until she finds a leading American neuroanatomist willing to help Henrietta unlock her son's brain and unleash his physical and cognitive potential.

There are many excellent reviews of this book on Amazon, including reviews written by parents of other disabled children thanking Henrietta for having the courage to write the book and speak out for the hundreds of families who have to fight for everything their child needs.

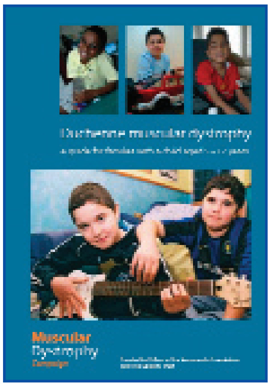
Give it a go…
Joanne McConnell

Henrietta's Dream is published by Hodder & Stoughton, ISBN 034083157X

Muscular Dystrophy Campaign – Booklets and Guidelines

Sally Otter, Head of Marketing & Communications, Muscular Dystrophy Campaign

Duchenne 5-12: A guide for families aged 5-12



The Muscular Dystrophy Campaign has published Duchenne muscular dystrophy: A guide for families with a child aged 5-12, a follow up booklet to its initial guidance on a new diagnosis. The publication covers medical issues, mobility, housing and equipment, schools, holidays and family matters. Written by one of the charity's care advisors, Jane Stein, the booklet is a valuable companion to families, as well as teachers and healthcare professionals. It is available for free.

An introductory guide for families with a child newly diagnosed with muscular dystrophy or an associated neuromuscular condition

Two of the Muscular Dystrophy Campaign's care advisors have joined forces to write a booklet for families who have a child newly diagnosed with a neuromuscular condition. Jane Stein and Julie Cassell wrote the guidance which covers sensitive issues around diagnosis and how to cope with the information. It also looks at wider questions around how to break the news to family and siblings, and the impact the diagnosis will have on the child's future, as well as how family members can support each other. Useful contacts and support groups are listed

Inclusive education for children with muscular dystrophy and other neuromuscular conditions – guidance for primary and secondary schools

In 2004 the Muscular Dystrophy Campaign launched its well-received guidelines to inclusive education for primary and secondary school children with muscle disease. April 2007 sees it publish, in partnership with Norwich Union, a 2nd edition of the guidelines, which incorporates feedback from thousands of teachers and families who used the publication, as well as updated information in line with recently published and relevant academic papers.

The guidelines – 120 pages long – covers in depth issues such as access to schools and curriculum, emotional and psychological issues, adaptations to the school, statutory assessments and transition. This comprehensive approach to inclusive education for children with muscle disease has been deemed an invaluable support by schools and families. Two booklets aimed at children with muscle disease are included in appendix 2 as well as a booklet written to help other pupils understand the needs of a classmate who has muscle disease. The guidelines are available free to teachers and parents.

These 3 booklets are available from:
publications@muscular-dystrophy.org
Tel: 020 7819 1814

Innovation for Health: Making a Difference
Government and industry highlight benefits of innovation in the NHS

The Government and the medical devices industry have recently published their report *Innovation for health: making a difference*. It sets out plans for acceleration of the use of medical innovation more widely across the NHS for the benefit of patients. It also gives a clearer picture of what the medical device industry needs in order to grow and prosper.

This report is the culmination of the joint work taken forward by the Strategic Implementation Group which was set up by the Healthcare Industries Task Force (HITF) to oversee the implementation of the 9 key HITF outputs.

Health Minister, Lord Hunt, said: "Medical innovation has a major role to play in helping the NHS improve quality of life for patients. This report outlines the achievements gained by Government and industry working in partnership and the further benefits to be realised from our continued co-operation"

At its final meeting on 26 February 2007, the Strategic Implementation Group agreed six recommendations to take forward:

- working toward the adoption and implementation of the **procurement framework** by the NHS involving key stakeholders, including patients, clinicians and industry. The framework will support the uptake of technologies and innovations which can lead to improvements in healthcare provision, patient safety and value for money.
- a stocktake of **existing support mechanisms and of access to private finance for small and medium sized (SMEs)** medical device companies and a review of what measures would be needed to address any issues that are identified.
- development of a **UK marketing strategy** covering both inward investment and export opportunities for the main industry sub-sectors.
- **measurement and analysis of the UK healthcare industry environment** – further development of key indicators to focus on success factors related to innovation, trade surplus and inward investment.
- Government and industry to play an active role in the European Commission's inquiry into the **competitiveness of the European medical devices industry**.
- creation of a new mechanism for

continuing the engagement between Government and industry.

Sir Christopher O'Donnell, Chief Executive of Smith & Nephew, said: "Putting patients at the centre of all that we do is the key to aligning the interests of the Government, the NHS and industry. By focusing on mechanisms which accelerate the rate at which innovative treatments get from the laboratory to the front line of NHS care, we can create a virtuous circle. Patients should get the best treatments in a timely manner and our industry seeks to convert the creativity of doctors and scientists into innovative technologies to achieve this."

Collaborative working with key stakeholders has enabled practical measures and mechanisms to be identified to help improve patient access to the latest treatments medical technology companies can provide. Key achievements include:

- establishment of a **National Innovation Centre** which is already beginning to link innovators with appropriate financial, clinical and commercial partners to help them bring promising new products successfully to market
- **inclusion of medical devices** and technologies within the work programme of the **UK Clinical Research Collaboration**
- development of **a new device evaluation service** (the Centre for Evidence-based Purchasing) within the NHS Purchasing and Supply Agency (NHS PASA) to provide objective evidence to support uptake of useful, safe innovative products
- **development of a procurement framework** for the NHS to embed modern approaches to procurement in the NHS and to deliver increased value for the service of patients
- **launch of a training hub** to support use by the NHS of advanced training tools **for key innovative surgical procedures**
- development of **two pilot Healthcare Technology Cooperatives** from April 2007 to pioneer new technology-based treatments in areas of unmet clinical need.

Background Notes

1. The healthcare industry in the UK is made up of over 2000 companies producing a wide range of medical equipment and devices, ranging from syringes and aids for the disabled to diagnostic test kits, pacemakers, high technology scanners. Companies include both major international players and small organisations manufacturing niche products.

2. HITF came about because of the healthcare industries' wish to develop a strategic dialogue with Government. Launched in October 2003, it was a joint year-long initiative which addressed a number of issues of common interest and developed solutions or improvements that would bring benefits for patients, the NHS, the national economy and industry. It focused on market access, R&D and the industrial base, regulatory issues and international trade. The emerging theme was how to stimulate innovation in the NHS and industry and how to increase adoption of new useful medical technologies.

3. The Task Force published its report *Better health through partnership: a programme for action* in November 2004 which set out nine key actions:
   - development of device evaluation under the new *Centre for Evidence-based Purchasing (CEP)* to support more intelligent procurement
   - more professional approach to procurement, involving clinicians in regional Collaborative Procurement Hubs
   - creation of a National Innovation Centre (NIC) to support promising new products through development to adoption
   - building R&D capacity via the UK Clinical Research Collaboration (UKCRC) to promote more clinical trials with medical devices and technologies in the NHS
   - development of Healthcare Technology Co-operatives (HTCs) to pioneer new medical technologies in partnership with the NHS, industry and academia
   - enhancement of the UK role in international regulatory issues via the Medicines and Healthcare products Regulatory Agency (MHRA)
   - development of a focused export strategy
   - development of training and education in the area of medical technology to ensure staff have the appropriate competencies
   - improved communication with patients, public and healthcare professionals on the regulatory regime and safety profile of medical devices and technologies

4. Background to HITF, the HITF report and the SIG report can be found at the DH website www.advisorybodies.doh.gov.uk/hitf

5. The UK Clinical Research Collaborative (UKCRC) is tasked with speeding up the development of new medicines and treatments from the laboratory to the patient by expanding the number and range of clinical trials. Its aim is to help bring together clinical teams, primary care trusts, the voluntary sector and industry to increase the number of patients participating in clinical trials. Its work will initially be targeted on five therapeutic areas. It is chaired by the Director of R&D of DH and the Board comprises representatives of the main UK funding bodies for clinical research (Departments of Health – England, Scotland, Wales and Northern Ireland, OST and MRC, the Association of Medical Research charities, the Wellcome Trust, UK Cancer Research, related industry sectors, the Academy of Medical Sconces and the Academy of Medical Royal Colleges), the NHS Confederation, an SHA, MHRA, NICE and the public.

6. The leading trade associations worked together, being represented by the British Healthcare Trades Association (BHTA), the British In Vitro Diagnostics Association (BIVDA), the Association of British Health-Care Industries (ABHI), the Surgical Dressing Manufacturers Association (SDMA), the British Association of Anaesthetic & Respiratory Equipment Manufacturers Association (BAREMA), GAMBICA (representing the interests of companies in the instrumentation, control, automation and laboratory technology industry), the Association of Healthcare Technology Providers for Imaging, Radiotherapy and Care Manufacturers (AXrEM), and Medilink UK which includes Mediwales, Medical Devices in Scotland and Bio Business Northern Ireland.

Link is on the PMG website: **www.pmguk.co.uk/Home/Government+Initiatives**

CSCI information Paper, January 2007: "Growing up Matters – Better transition for young people with complex needs"

Summary by Helen Hislop, Haringey Wheelchair Service, PMG Communications Sub-committee

Transition from child to adult services can be a time filled with uncertainty for young people and their families. Ensuring a smooth transition can result in greater independence and wider opportunities for the young person as well as ensuring efficient use of service resources.

This paper from the Commission for Social Care Inspection uses information from qualitative interviews with 22 young people, parents & families, 179 senior managers in children & adult social services and their partners in health and education, as well as with 47 care professionals and managers in residential schools.

Transition protocols, the information provided to young people and their families, placement criteria, joint assessment documents and commissioning strategies were also studied to illustrate areas for improvement at all levels. Good practice case studies are dotted throughout the paper and serve to highlight how little national consistency there is in managing this time of life.

See the full report on the website of the Commission for Social Care Inspection: **www.csci.org.uk**

Don't Forget…

To confirm your PMG membership details online and Cancel your Standing Order to PMG

See page 8

Keith Parfrey

10th September 1939 – 8th March 2007

It is with great sadness that we report the recent death of Keith Parfrey who worked for many years as a Rehabilitation Engineer within the Wheelchair and Special Seating Service in Bristol.

Keith and his wife Geraldine had recently celebrated their ruby wedding anniversary with a family party. Keith and Geraldine then went on a celebratory holiday to Madeira where he succumbed to a heart attack. Our deepest sympathies go out to Geraldine and their daughters, Katie and Louise.

Keith was brought up in Bristol and attended school in Speedwell. Following on from an engineering apprenticeship he joined the Civil Service in July 1965. His career took him all over the South West of England including spells working at Exeter DSC as a Technical officer for 11 years. In September 1988 he was promoted to Rehabilitation Engineer based at Portsmouth where he worked for a further 2 years until he joined us in Bristol in 1990 to work with the wheelchair and special seating service.

Keith partially retired in September 2001, coming back to work part time until he finally retired from the Trust in September 2003.

Keith was a member of PMG from the start of the Group until his retirement and always enjoyed and supported the conferences.

Keith had a dry sense of humour, but it was always there, just under the surface. He was totally dependable, always prepared to offer advice to anyone who asked, with no regard for any personal sentiment. He worked tirelessly and selflessly in the wheelchair and special seating service through huge and far reaching change: McColl, the DSA days, Regional Health Authorities, new, naïve managers, and even the advent of the occupational therapists. We always joked that Keith had been around as long as wheelchairs themselves, such was his knowledge base. His career covered most aspects of Rehabilitation Engineering, from prosthetics to the 3-wheeled blue cars. Keith always had a story to tell, and it always made you laugh or taught you something. He put the needs of the service and service users ahead of any personal preferences: a true professional.

If he needs a legacy, then look around at the Rehabilitation Engineers, no, at the whole clinical team, in Bristol. Keith was always there for the new member of staff to help, support, and be the sounding board. We all owe him a debt for the knowledge he was always prepared to share.

I will always treasure the Friday afternoons we used to spend with a sneaky cigar behind the wheelchair offices putting the world to rights. You knew he, and the other engineers, would take the Mickey, but it was always a pleasure to share the time. Of course we all gave up the smoking. Keith never gave up the Mickey taking!

Henry Lumley and Martin Moore

Two kids in their newly-delivered chairs, all set for an exciting summer ahead

< Playtimes will be
different for Maddy
from now on…

Freddy wants to know >
who chose this gravel!

Pictures courtesy of Whizz-Kidz

Children and Young People's Services Annual Conference 2007

Thursday 24th May 2007
The Academy Conference Centre, Holiday Inn, Carburton Street, London W1

Programme includes: "Making every disabled child matter"
Speakers – Steve Broach, Campaigns Manager, Every Child Matters, NCB
Francine Bates, Chief Executive, Contact a Family
Keynote speakers – Beverley Hughes MP, Minister for Children, Young People & Families
Rob Williams, Chief Executive, Office of the Children's Commissioner

Further details: Parvin Madahar, Director, Westminster Briefing
Tel: +44(0)20 7096 2916, Email: parvin.madahar@westminster-briefing.com
www.westminster-briefing.com

Interconnections Electronic Bulletin

Peter Limbrick set up Interconnections in 1995 to offer independent consultancy to statutory services in the field of babies and children who have disabilities/SEN. He is also Chair of the Handsel Trust (***www.handseltrust.org***)

The Interconnections Electronic Bulletin goes free to over 8,000 people (and growing) in all parts of the UK and Ireland and then finds its way into many other networks and countries. The Interconnections electronic address list includes people from health, education and social services, the voluntary and private sectors, parent organisations, research organisations, campaign offices, etc. People who receive the bulletin are welcome to forward it to their own colleagues and networks and to use the information in their newsletters and bulletins.

Tel/fax: 01497 831550 E-mail: p.limbrick@virgin.net

"In Control of My Body" Postural Care Experiences from the UK and Australia

24th May 2007

York CVS
15 Priory Street, York, YO1 6ET

Details from Anna Goldsmith at
Postural Care Skills on 01827 304938

Association of Wheelchair Children: Wheelchair Skills Training

29th & 30th May 2007, Torquay: 2 Day Manual
31st May 2007, Torquay:1 Day Electric
9th June 2007, Kendal: 1 Day Manual
10th June 2007, Kendal: 1 Day Electric
30th June & 1st July 2007, Warrington: 2 Day Manual
7th & 8th July 2007, Neath

For further information,
see contact details on page 16

The NAEP Annual Conference

27th and 28th June 2007
Britannia Norbreck Castle
Hotel, Blackpool

01278 751194 or
jobs4healthcare@aol.com

Michael Hare's Homepage

http://michaelehare.googlepages.com

Papers and Guidance Documents Concerning Wheelchairs
and Special Seating – Their Use,
Supply, and Maintenance

Includes information about the following:
NVQ2 Maintenance and Installation of Mobility Equipment Course

Transforming Public Services Through Third Sector Partnerships: Removing Barriers

27th June 2007, 10.00 – 16.15

The Academy Conference Centre, Carburton Street,
London W1.

Further details:Mark Sundhu,
Research & Development Manager,
Westminster Briefing

Tel: +44 (0)20 7096 2920
Email: mark.sundhu@westminster-briefing.com

www.westminster-briefing.com

CALL FOR ABSTRACTS

Calling for abstracts from *ALL* fields of
Occupational Therapy with Children,
Young People and Families for the

1st CYPF Conference

"Thinking Reflectively – Acting Dynamically"

Wednesday 14th & Thursday 15th November 2007
Hilton Grosvenor Hotel, Edinburgh

Contact: Viv Chamberlain or Trisha Nutter
Therapy Learning, PO Box 8392,
Melton Mowbray, LE13 9AX
Tel: +44 (0)1159 250910
Email: enquiries@therapylearning.co.uk

www.medrehab.net

This is a website from the USA run by physiotherapist Adrienne Bergen. She posts articles and case studies on the website, as well as giving a forum to discuss day to day challenges.

Adrienne goes around major US exhibitions such as Medtrade and ISS, and writes up reports of what's new from different manufacturers (to be found under Articles/Conferences and then click on the blue hyperlink). From March's ISS she has 3 reports and from last autumn's Medtrade a total of 26. They are fully illustrated, and give a bird's eye view of what is becoming available for everyday use.

The Jennifer Trust AGM and Conference

30th June to 1st July 2007

Ettington Chase Conference Centre, Ettington, near Stratford upon Avon.

For conference programme and booking details go to:

www.jtsma.org.uk/conference

Assistive Technologies Magazine

is for healthcare professionals, experts and association businesses who have interests in assistive technologies and mobility improvement.

It covers the disciplines of rehabilitation, orthotics, prosthetics, and orthopaedics as well as associated specialists in fields such as occupational therapy, physiotherapy, and mobility engineering

www.assistivetechnologies.co.uk

IPEM Annual Scientific Meeting and IBEX 2007 Exhibition

10th – 12th September, 2007

Innovation in Healthcare

www.ipem.ac.uk/ipem

Whizz-Kidz Regional Centres

Birmingham Mobility Centre
Mobility Centre, Prospect Hall, College Walk, Selly Oak, Birmingham, B29 6LE
Contact: Laura Evison Tel: 0121 4723261

Newcastle Mobility Centre
Mobility Centre, The Dean Centre, Castles Farm Road, Jesmond, Newcastle, NE3 1PH
Contact: Louise Forrest and Jenny Crosby Tel: 0191 213 6770

Whizz-Kidz & Tower Hamlets NHS PCT
Wheelchair Service, Mile End Hospital, Bancroft Road, London, E1 4DG
Contact: Ian Legrand Tel: 020 8223 8302

STOP PRESS: NEW partnership initiative for children in London

Whizz-Kidz and the Tower Hamlets PCT launched a new pilot partnership in March this year with the support of Ed Balls, Economic Secretary to the Treasury and local families. The goal is to deliver an enhanced service for children in Tower Hamlets and London-wide through joint assessments, pooled expertise, and resources. The pilot is being supported by Lydian Asset Management and will run initially for 3 years. To see the full story log onto www.whizz-kidz.org.uk

For more information or calendar of events for each centre, go to the website, contact the 'centre' direct, or email: info@whizz-kidz.org.uk

MAVIS Closed

The Dept of Transport's Mobility Advice & Vehicle Information Service (MAVIS) closed at the end of March 2007. In future driving assessments will be made by the Forum of Mobility Centres.

National Enquiry Line: 0800 559 3636   www.mobility-centres.org.uk

The Oxford Centre for Enablement, Nuffield Orthopaedic Centre NHS Trust, Headington, Oxford, OX3 7LD

Course tutors: Wendy Murphy and Pat Postill

Posture Management of People with Complex Disability

27 – 29 November 2007

An introduction to the issues pertaining to the physical management of children and adults who have profound and complex disability. Suitable for Allied Health Professionals working in neurological and neuromuscular disability.

Course fee: £285.00

Posture Management of Adults and Children with Complex Disability: Post graduate certificate

The course is run annually at the Oxford Centre for Enablement, in collaboration with Oxford Brookes University (OBU). Successful completion of this course awards you a post graduate certificate and is worth 1/3 of a Master of Science degree (if you go on to study for the degree at OBU) and up to 40 CATs points (if you study at another university).

Taught weeks: 2 – 6 July 2007, 1 – 5 October 2007, 21 – 25 January 2008,
Follow-up day 27 June 2008

Course fee: £1,950.00

Contact Tom Postill, Course Co-ordinator, for details -
email: coursecoordinator@noc.anglox.nhs.uk
Tel:01856 227879

Posture Management for Children and Adults with complex disabilities

Wendy Murphy MSc MCSP from the Oxford Centre for Enablement -
in association with Chunc and Martha Trust, home for profoundly disabled young people in Hereford

This course comprises two days at Martha Trust in Hereford with a follow up day some weeks later. Theoretical and applied sessions provide a background to the posture management of the severely disabled person. Management is essential in order to optimize remaining functional ability and minimize secondary complications associated with this client group.

The specialist field encompasses a wide range of issues. As new developments occur in the social, medical and environmental paradigms, so the depth and complexity of knowledge and skills required to be able to adequately define and manage the therapeutic needs of the client group expand.

The follow-up day provides participants the opportunity for the application of the theory in the workplace by working on case study, returning to consolidate the learning.

This course is suitable for Allied Health Professionals working in neurological and neuromuscular disability.

Course Tutor

Wendy Murphy is Therapy Education Coordinator at the Oxford Centre for Enablement. She is a state registered physiotherapist, has a Master of Science Degree in Evidence-Based Health Care, University of Oxford & a Masters Certificate in Teaching in Higher Education, Oxford Brookes University.

She is a member of specific interest groups Association of Pediatrics Chartered Physiotherapists (APCP), Association of Physiotherapists in Neurology (ACPIN) and Medical Legal Association of Chartered Physiotherapists (MLACP).She is a very experienced clinical practitioner in the field of paediatric and adult disability arising from neurological dysfunction.

Course dates

25th and 26th June follow up day 6th Sept.07
18th and 19th Sept follow up day 1st Nov.07
20th and 21st Nov follow up day 24th Jan 08
5th and 6th Feb follow up day 17th April 08
3rd and 4th June follow up day 10th July 08

For booking form and further details contact the course administrator:
Lucie Rivett, Specmat Ltd, Chunc Wheelchairs, Tarsmill Court, Rotherwas, Hereford, HR2 6JZ.

Tel: 01432 377512 *Email:* **Lucie@chunc.co.uk**

Ade Adeptian, patron of AWC, teaching youngsters basketball skills
(see the article on page 16 for more information).

Next Issue… The NTE 2007 Special Edition

We hope this lovely image will inspire you to put pen to paper and write about your experiences at NTE 2007. The NTE special edition is due out in the autumn. Please send your copy, with photos if you have them, to:

olwen.ellis@pmguk.co.uk

(before September 7th 2007)

Warwick Conference Centre at Night
Photographed by Clinton Davin of South West Seating

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