

# POSTURE & MOBILITY

Volume 10 Autumn 1999



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from left to right: Robin Luff 2001, David Thornberry 2000, Roy Nelham 2002, Phil Swann 2001 (front), Rene Parison 2002, Julia Cunningham 2002, Patsy Aldersea 2001, Christine Turner (front) 2001, Barend ter Haar 2001 (hiding), Dave Calder Co-opted, A.N. Other vacant committee space from 1999.

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The next issue of Posture & Mobility will be in May/June 2000. The deadline for this issue is the 20th of March. The aim of the 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, should be between 500 and 2000 words, photos and/or cartoons are welcome as are jokes and mindbenders etc. Please send contributions printed (Times New Roman bold 12pt) or (preferably) on disk.

The PMG Newsletter is published by the Posture and Mobility Group. The views expressed are those of individuals and do not necessarily reflect those of the Group as a whole.

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#### **Editorial**

Greetings to a belated 10th issue of posture and mobi lity.

Special thanks to all those who reported on the 99 annual conference at Glamorgan: Patsy Aldersea, Barend ter Har, Julia Cunningham and Rene Parison.

This is the fifth issue under the current editorial team and we would welcome comments from the membership on 'Posture and Mobility'. Is the content appropriate? Is it interesting? Are there subjects of particular interest you would like reported? Please comment on these questions and more by responding to the survey. The results will be published in the next issue.

Dotted about you'll find pictures from the Glamorgan conference, one or two of the offerings I had to censor! This years competition is open for the best doe-see-doe, good to see Robin Luff has another fine entry. You'll find a section in the survey for voting.

Apologies to those waiting for the sequel to 'Helping Gravity Help You', not enough space I'm afraid. It will however appear in the next edition.

In order that reports from the conference get out as soon as possible to the membership, the next issue will be published in May. The cycle will hopefully be back to every six months (May/November) following this.

#### Phil Swann

Editor

#### Letter from the Chairman

I feel privileged to have been elected as your Chairman for the next three years and I will aspire to at least maintain the excellent standards set by your previous Chairmen. On that note, I would like to acknowledge the sterling service provided during the last three year term by Robin Luff who, with his clear vision and none too few contacts in the right places was able to steer the group into the respected organisation it is today. As Robin remains a member of the Committee I will no doubt be calling on his assistance at least during the coming year. Robin will continue to represent PMG on British and International Standards groups and any comments you may have on standards work currently under way relating to the interests of the PMG we will be pleased to received either for discussion at Committee to assist with our representation or as a publication within Post Bag.

In the Spring 1999 edition of Posture and Mobility, in the Post Bag, we received two contributions from Robin Luff and Patsy Aldersea regarding the need to approach postural management in its widest context. Both letters addressed the funding issues associated with such a move and it seems that the PMG should be taking a lead in pursuing this approach. The PMG, however, is only as strong as it's membership. In order to begin to identify appropriate ways forward for the development of standards of practice and guidelines we must have a consensus view otherwise we represent nobody. The 2000 Conference planned in Llandudno (try saying that while you are eating!) will address the issues of "Working Together". The subheading of the meeting is "The Whole is Greater Than The Sum of the Parts" which is undoubtedly true of any cohesive activity. In the programme we have allowed a relatively long slot for all participants to raise problems they have experienced of working together. This includes working with different agencies, funding barriers to integrated services, the work of specialist centres or specialist services and any other issues which you have experienced as being a barrier or an inconvenience to working together. Later in the programme, we have two sessions devoted to workshops which will specifically address the problems raised in this first session. The objective will be to identify solutions and appropriate ways forward which can be tackled locally or which can be used by the PMG Committee as a consensus view in tackling the problems at the appropriate level. It will be important, therefore,

that we have the maximum input to these sessions from all participants at the Conference to ensure that we are identifying valid solutions and constructive ways forward. My attention was focused on issues of working together by Patsy Aldersea during our train journey from Llandudno back to London. She was able to describe in detail the problems experienced by some wheelchair services when specialist centres (like Chailey Heritage?) provide equipment that cannot be supported locally or raise expectations that cannot be provided for locally. These are real issues that can be addressed through greater understanding and better communication. I sincerely hope that the outcome of our Llandudno Conference will be a clearer way forward to more successful and more effective service delivery for our client group.

Llandudno is fairly full during the Conference with a result that our delegates will be spread around a few hotels in the town but all very close together and the majority within easy walking distance of the Conference Centre. Hotel lists will be sent out to registering delegates and early requests for accommodation will assist with first choices being fulfilled.

The provisional programme for the Conference is published in this newsletter and I look forward to seeing you all there and to enjoying your participation throughout the duration of the Conference. You will note, that because of the distance most people will have to travel to Llandudno, we have timed the meeting to fit in with the arrival and departure of the London to Holyhead train which can be picked up by other travellers at various points along the line. Hence we are starting at lunch time on Monday the 10th April and finishing around lunch time on Wednesday 12th April. Transport to and from the station is available and details of this will be sent to you with your Conference pack.

Be there and help us to work towards an integrated approach to 24 hour postural management. Encourage your colleagues outside of the wheelchair services with whom you work to help us in this process by attending this meeting. It is a large venue and there is room for everybody, but book your place early. fog atellan

Roy Nelham

Chairman

# Turning an idea into reality: The evolution of the Jenx Major Buggy Insert

#### Introduction

The Maclaren Major Buggy has long been used by wheelchair services as a means of transit for children with mobility problems. It is a simple carrier for the older child and in it's original form does not meet the needs of children with poor postural control. However, despite it's apparent unsuitability the Major Buggy has in my experience been a popular choice amongst parents and carers of disabled children. The main feature is that the buggy is lightweight, easy to push and to carry. It also folds compactly for easy storage in car boots, buses or airplanes. Sadly, the Major Buggy suffered from it's appearance. Unlike other Maclaren buggies the canvas design has rarely been changed over the years. Many parents have commented to me that the buggy would better in a modern canvas in keeping with the other Maclaren models. Numerous attempts have been made to utilise the Major Buggy frame for supportive systems ie: Snug, Roebug, Klippan, Taylor therapy. However, these improvements in postural support were gained at the expense of the buggies original good features; lightness, ease of folding, compactability and price.

The development of the Major Buggy insert in the early 1990's spanned a number of years and was based on clinical experience backed up by basic qualitative research. It was initially created to meet the needs of one child and his family and then trialled on children attending the Ronnie MacKeith Child Development Centre who were unable to sit without support. The insert was never intended to provide the postural support which can be obtained in wheelchairs, other special buggies or home chairs. It is a compromise which allows a degree of symmetrical postural support and comfort during transit, whilst maintaining important lightweight properties. This paper outlines how the insert design was developed and finally produced through a collaboration between myself and Jenx Ltd a renowned producer of paediatric special seating who offer a yearly award for innovation to paediatric therapists.

#### Background

#### The initial design

The first insert (figure 1) was created in response to the postural needs of an athetoid child who lived in a hilly

with his parents both of whom had back problems. They used an ordinary Maclaren Tourer, too small for the child, rather than accept a wheelchair and were reluctant to consider anything they did not feel was aesthetically pleasing or lightweight. They also disliked webbing straps and worried about them rubbing on or digging into their child's skin.

#### Aims of Design

- ☆ To improve comfort.
- ☆ To maintain lightweight features.
- ☆ To maintain easy to fold features.
- ☆ To keep compact when folded.
- ☆ To fold with insert and cushions in place.
- ☆ To be aesthetically pleasing.
- ☆ To be affordable to produce.

#### Table 1 Aims for insert related to carers needs

This first insert was nicknamed the "Sumo Seat" because of the appearance of the straps. My aims for the user (table 1) and the child (table 2) evolved from my attempts to meet the needs of this family. The compatibility of the aims with the needs of a wider population were tested later using the investigative methods explained further in the text.

Table 2 Postural features required of the insert

#### Postural features of the insert.

Adjustability: To cater for the needs of a variety of special needs children.

**Lightness:** So does not affect stability of buggy.

Improved hip control: To stop the child's hips from slipping.

Improved trunk support: For children with weak/floppy trunk unable to maintain a central position when in static or moving buggy.

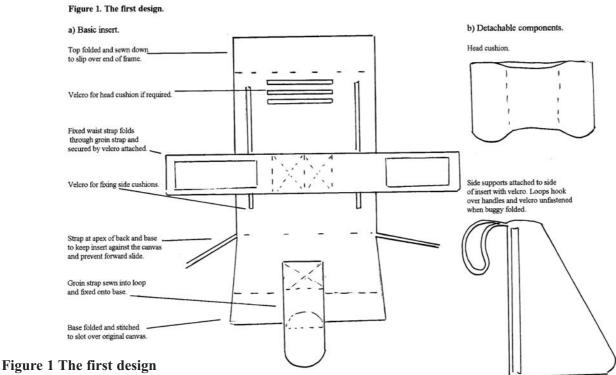
Head support: For children when tired or with poor head control when in moving buggy.

**Protection:** To prevent arms trapping between uprights and to protect from bruising.

Secure base: To ensure insert does not slip and affect the child's sitting position.

**Soft appearance:** To gain firm control whilst avoiding webbing straps and "D" rings.

A cover of padded, decorative fabric was made which



fitted over the existing seat cover. Straps wrapped around the base and rear of buggy to keep the insert from moving on the original canvas. Side pads were fixed to the back piece with velcro, to facilitate removable when the buggy was folded. they could be looped over the buggy handles to prevent them getting lost. The groin strap essential for keeping the hips back, was narrower than the Jenx version. The hip strap was designed to wrap around the pelvis across the top of the thighs. It did not insert at the apex of the buggy to pull the hips down into the angle of the seat as in other buggies as the groin strap helped prevent forward slide. The band was quite wide and the padding firm thus giving some lateral support to the lower trunk keeping the child central. Initially, the hip strap was fixed into position and could not be altered as the child grew. Altogether there were too many detachable parts for convenience when folding. Furthermore, the side pads slipped as there was nothing to fix them to the front uprights, see figure 1.

#### Further inserts

The second design (figure 2) was made for a very floppy child who also had severe drop fits and who required head and trunk support. Other special buggies had been loaned to this child but failed to provide the necessary support , didn't fit the car boot and hurt the mothers back on lifting them. By this time I had realised that the insert might have a wider application and could possibly be more widely adapted given a few design changes. This version was therefore built to accommodate growth. Two were made and the spare was put into

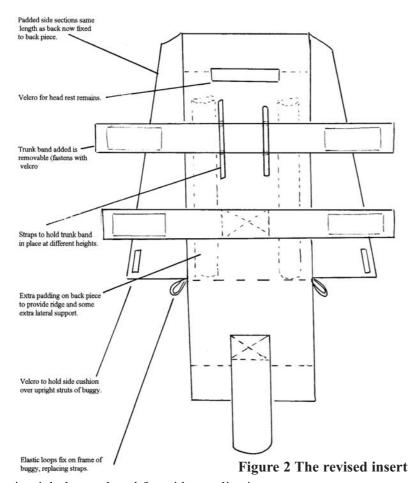
given to the nursery attached to the child development centre. It was used by children with severe dystonic athetosis, spastic quadraplegia. and severe leucodystrophy, see figure 2.

Side covers were incorporated into to the main insert so folding could occur without removing any of the insert. They were secured around the uprights by velcro tabs. Rolls of extra wadding were inserted into the edges of the back piece to promote a central position. A removable and adjustable trunk strap was added to allow for growth. A detatchable head cushion with lateral supports was also included. The groin strap was widened to promote abduction and a wider sitting base for better sitting but made fastening more difficult as at this stage it could not be opened up to ease threading. through of the hip strap. Securing straps holding the insert to the buggy were replaced by elastic fixators. Shower curtaining was used to make it more rain proof. Mouldable milliners interfacing was used to help it maintain it's shape after wear but it kept its shape too well and became difficult to fold. Extra padding was added to the base to combat the sag caused by the original canvas. The original securing clip which held it in the folded position was not long enough and was replaced with a velcro strap.

#### Feedback from users

Feedback on the proto-type was sought from parents and carers of the children using the insert in the nursery.and it was this that resulted in my decision to enter the insert for the Jenx award for innovation in the hope

Figure 2. The revised insert.



that it might be produced for wider application.

Parents & carers liked the simplicity and the appearance of the design and the absence of webbing straps and buckles. They reported that the children were happier in the insert than in other buggies or wheelchairs. (Interestingly, two nursery children were very unhappy each time they were taken out of the buggy and asked to go back in it).

Nursery staff appreciated the fact that the insert could be used for any child in the nursery without having to spend time making major adjustments. All found that it was still easy to fold, carry and store the buggy. and had no difficulties washing the insert. Nursery reported that the buggy was safely able to hold a 4 year old with a severe extensor thrust, The straps were able to contain the child without chaffing or digging in., allowing the extensor spasm to occur but containing it sufficiently to allow a return to the original position.. It was acceptable to those unwilling to entertain other options and who had previously continued to use baby buggies. Carers had also received positive comments from other parents/colleagues regarding the appearance of the insert.

#### Investigating wider applications

The insert may never have progressed beyond the initial model, had I not noticed that a number of parents were still using baby buggies and others whom I had known in the past were keeping hold of Major Buggies once wheelchairs had been provided. I often saw physically disabled children in the local shopping centre or park, seated in easy fold "umbrella" buggies clearly too small and unsupportive. Some parents had attempted to cover the Major Buggy with aesthetically pleasing fabrics. As previously stated this led me to explore why such buggies were preferred and what I could do to the insert to make it acceptable to parents.

My main method of investigation was to gain qualitative information through informal chats with parents of children attending Occupational therapy sessions and with other carers whilst they were waiting to see the paediatrician. I spoke to approximately 30 parents in this way. My aim was to identify common themes

surrounding the use / non use of the Major Buggy and baby buggies. Discussions were also held with Physiotherapy and Occupational therapy colleagues. Subsequently I was engaged in researching musculoskeletal stresses experienced by carers (Nicholson 1998) and in my survey of 118 parents had included a number of questions linked to wheelchair and buggy use (not included in the main study) which added to the data..

Parents questioned expressed a preference for the Major Buggy due to a combination of the following factors: It was the lightest special buggy available, easy to carry, easy to fold, compact when folded and looked most like an ordinary buggy. The local survey showed that 88% of parents of special needs children had chronic back problems (Nicholson 1999) which they felt was aggravated by the lifting and handling aspects of caring. These findings were echoed in a national study by Scope which identified an incidence of back pain amongst carers at 65% (Lamb and Layzells 1995). My research also showed that 16% of local parents with children over 5 years preferred to continue using ordinary or Major Buggies despite owning wheelchairs, reasons were appearance and ease of

handling. When questioned therapists were not keen on the Major Buggy or other umbrella style buggies for the child but they did acknowledge that they met the needs of the parent better as they were compact for storing in car boots, lighter and easy to pick up. Parents who expressed a dislike for the buggy objected to it's lack of support, old fashioned appearance of the cover, harsh feel of the canvas and the slippiness of the fabric. Maclaren did make an insert but it was seen to "bunch" the children up and to lack postural stability by parents and therapists. Athetoid children were reported to trap their arms in-between the uprights of the buggy. and children with low tone to bang their heads on the sides of the buggy due to poor support. Special seat inserts available at the time were not popular as they had a negative effect on the perceived good features of the buggy, for example as with wheelchairs, parents were unable to fold the buggy with supports in place. and the overall pushing weight increased significantly. The considerations of therapists were similar to the parents.

Table 3 Capabilities of the insert for users and carers

#### Capabilities of the insert.

- ☆ To address the carers need for an easy to manage mobility aid.
- ☆ To create an insert which improved support within the major buggy for children with mild to moderate postural needs.
- ☆ To address the needs of the severely disbled child using the major buggy by the addition of extra cushions and supports as necessary.

#### The development of a commercial product

Despite positive feedback from carers on the capabilities of the insert (table 3) and indications of a wider need for the insert, further developments were limited by my own capabilities. Finance was limited as was time to make and trial more inserts. My knowledge of materials was also limited and further work was required to find the most durable and waterproof fabrics and the best wadding. I was also aware that if the original lap strap was not to be used then a safety catch system would need to be included in the design. When the design the Jenx award the company expressed an interest in developing the idea further and producing the insert for the commercial market. The design to be then improved through consultation with Jenx's in house design team. Features now include (figure 3): a better lock for keeping the buggy folded, a clip for dummies or toys, removable lateral pads on the back to

cater for different sizes, more secure fastenings on the straps, and an adjustable groin strap.



Figure 3 Photo of Jenx insert

The insert has now been in full production for over a year and is sold both at home and abroad. It is popular as a transit chair for nurseries etc to transfer children quickly from taxis to the classroom. It has also been used in double buggies where two children in the family are disabled or where one child is disabled and the other too young to walk. Personally, I have found that it continues to work best for the young children with athetosis, ataxia and hypotonia and has been useful for children in early stages of recovery from meningitis, head injuries etc. A number of parents have purchased the buggy and insert in addition to the wheelchair they were provided with. Finally, Jenx have also opened up discussions with Maclaren regarding possible improvements to the basic design of the buggy.

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Nicholson J. (1999) "Management strategies for Musculoskeletal Stress in Parents of Children with Restricted Mobility" British Journal of Occupational Therapy May 62(5) 206-212.

#### JANET NICHOLSON.

Senior Paediatric Occupational Therapist.Ronnie MacKeith Child Development Centre.Southern Derbyshire Acute Hospitals Trust.

For more information on the Jenx Major Buggy insert contact: - Jenx Ltd. Tel 0114 285 3576. Fax: 0114 285 3528

# The fifteenth international seating symposium: Seating and Mobility for People with Disabilities

March 4th ~ 6th 1999, Omni Rosen Hotel, Orlando, Florida, USA

I was fortunate to attend this very stimulating symposium. Prior to the conference I attended a one day pre-symposium workshop presented by Bengt Engstrom, entitled "Seating and Wheelchairs - Interactive and Conscious". It was probably one of the most useful and thought provoking workshops I have attended. The one major concept I took away is this: Is what my client is doing (how they present at the seating clinic) pathological, or is it sensible (given the system they are in and the position we have put them into)? A person will always seek the most stable position that will allow them to function as they are able.

This workshop was experiential, and I found myself aching at the end of a long day of putting myself into different postures and, as Bengt said, "feeling it".

The seating symposium proper started with the Sunrise Medical Keynote Address, given by Simon Margolis, CO, ATP, ATS, CRTS. Entitled "A Seating and Wheeled Mobility Prospective Retrospective", this presentation challenged our ethical and moral practices as clinicians. The major question asked was this: "To whom do we owe ultimate moral and ethical responsibility?" Thought provoking indeed.

The general sessions kicked off with "Outcomes in Seating and Mobility Intervention" presented by Jean Minkel, MA, PT. Aiming to illustrate the impact research could have on our practices in this field, the presentation finished with a thought provoking quote from Dr. Helfland "We have to be guided by a combination of evidence, ethics, and judgment. 'Not proven' is not the same as 'proven not'. If evidence does not show that an intervention has good outcomes, it is your responsibility to make sure that more and better research is conducted." Challenging indeed!

Friday morning saw two tracks running concurrently: Pressure Management Research, and Clinical Case Studies. Both were very stimulating (I managed to flit between the two, attending the papers I was particularly interested in). The afternoon held two special sessions, one on Dynamic Seating, and the other on Transportation Safety. In the evening round table discussions were held, with more than 20 discussion

groups providing a wide spectrum for informal discussion.

Saturday morning held a paper session with four papers presented. **Chris Bar** delivered a paper entitled "**The Ethics of Ignorance**" which was thought provoking and created quite some discussion following his conclusion. He postulated that clinicians, manufacturers/suppliers, and academics need to work together to achieve common goals, and benefit the industry as a whole.

Finally the special session, titled "The Future is Now" held four papers presenting the latest developments in telerehabilitation and the world wide web. The research being conducted in this area appears to be very exciting, and will seriously impact the clinician at the grass roots.

As well as the paper presentations, there was an exhibit hall filled with commercial and non-profit organisations. There was plenty of opportunity to explore technical seating and mobility technologies. The exhibit hall also hosted several instructional courses, using state of the art technology. It was heartening to see new technologies being launched at this symposium, and existing technologies being demonstrated, however begged the question of when will we see this technology in the UK.

The programme objectives were to identify seating and mobility interventions for people with physical disabilities; to discuss service delivery practices; to know current research; and to recognise seating and mobility technologies. These objectives were certainly reached from my perspective. To summarise, the majority of papers were presented by clinicians who carried out research as part of their clinical practice, rather than 'academic' researchers. The overwhelming themes throughout the symposium were the importance of evidence-based practice, the importance of measuring whether what we do is effective (outcome measures), and the importance of communicating the effectiveness of what we do. The atmosphere generated by over 800 people all interested in wheeled mobility and seating was most stimulating. It was very nice to put faces to names of the people whose articles and books I have read.

The call for papers has gone out for the Sixteenth International Seating Symposium, to be held in Vancouver, British Columbia, Canada, from 24-26 February 2000. I challenge readers to seriously consider submitting a paper for this meeting.

Acknowledgement to the College of Occupational Therapists for the award of the Margaret Dawson Fund 1999 which supported in part the funding of attendance at the Fifteenth International Seating Symposium.

Emma Parry Clinical Director - SCAMP, Centre for Disability Research and Innovation, Royal Free and University College London Medical School.

"A Team Approach to Children's Mobility" convened by Whizz-Kidz held at "The Asthton Court Mansion, Bristol Wednesday 9 June 1999

This was the first one day conference arranged by Whizz-Kidz and was aimed at a general audience of children, parents and carers together with local therapy teams and specialists. I was invited to chair the meeting whilst I was still Chairman of the Posture and Mobility Group. Whizz-Kidz kindly continued their offer despite my relegation to the ranks of committee member before the date of the conference. The conference itself was held in a magnificent mansion a little outside Bristol. I remember this very well since my wife and I used to walk through the grounds of Asthenia Gate in our courting days.

The meeting was full to overflowing and the delegates comprised a wide spectrum of providers and users of all sorts of paediatric wheelchair and mobility services. Chris Drake, an orthotist well known to many of us working in the field of paediatric orthotics and posture, gave a presentation on "the importance of team approach to child mobility" in which he demonstrated and emphasised the roles of each of the team members with understandably an emphasis on the linking role of an orthotist in many of the more complex presentations. The audience was then presented with a tour deforce about independence in wheelchair selection by Bonnie Chamberlain who despite profound physical disabilities has led a full and active life. Her presentation was enabled by Bonnies's mother who was able to expand in subsequent discussion on some of the many issues that Bonnie raised about "her perception of her involvement and control over selection of her wheelchair." She now drives a sophisticated powered chair which is black.

response to my question as to why she chose black she said "because it is cool". Ashton Gate is a delightful old rambling building and it proved very difficult to bring delegates back into order in time for the start of the next session. I discovered that the organisation has a large handbell which proved very effective. There were then presentations by Wendy Dakin, who is a Paediatric Occupational Therapist in private practice, who described "her views of the input of occupational therapy" into a sensitive team approach to wheelchair selection. Madeline Sdurski from Capability Scotland gave a similar presentation but from the "physiotherapist's perspective". There was a comprehensive exhibition of mobility aids of all sort with a strong paediatric bias. An hour was given for the exhibition and this gave a chance for many fruitful discussion both with colleagues and individuals.

The afternoon session was opened by Mrs Sally Woods who has a son with muscular dystrophy. Mrs Woods worked with children with disability before becoming a mother and made a number of telling points both from a "parent's perspective and from the professional social work perspective." She really concentrated on the feelings of parents who are involved in the process of selecting equipment for children with disabilities. Gerald Simonds from Gerald Simonds Healthcare closed the session with a presentation on "the dealer's role in teamwork" in equipment selection. He emphasised the importance of ethical considerations in commercial concerns involved in healthcare for children in particular and this gave rise to a healthy discussion around the apparent variations in quality of corroboration with private resources. The final session contained presentations by two professions. Philip Swann, Clinical Engineer at the Royal National Orthopaedic Hospital, discussed how a multidisciplinary team from the Health Service could and should interact with families and with private resources in terms of bringing about the best possible result in any single situation, This concept was taken on by Henry Lumley, the manager of the Bristol Disablement Services Centre who is well known to many of us in terms of his great interest in developing wheelchair services. Henry developed some very exciting concepts of useful and important interactions between statutory wheelchair services, private purchases and suppliers in terms of producing a genuinely comprehensive team approach to the provision of technical aids for children with disabilities.

I then had the pleasure of summarising the meeting and

thanking what proved to be a most effective faculty of speakers. I obtained the text of Bonnie Chamberlaine's presentation and have passed this to the editor of this bulletin for future publication. I understand from Whizz-Kidz that this conference will be the first of a series and I look forward to the successful development of this worth while initiative on behalf of paediatric users of wheelchairs and other mobility aids.

**Robin Luff** Consultant in Rehabilitation Medicine, King's Healthcare Rehabilitation Centre

### Lightening the load 13/08/99

This one day Seminar was held between Merton & Sutton Wheelchair Service and Banstead Mobility Centre. The aim to share ideas, problems, successes pertaining to the assessment of provision of EPIOCs.

The programme opened with an informative and practical presentation by **Mike Knapp** on programming controls, care of batteries and chargers. Group discussion time and a practical session followed with two invited speakers, Alan Lynch, Head of the Wheelchair section of MDA and Ann Frye, Head of the Mobility Unit at DETR. during the afternoon session.

Alan Lynch provided a wealth of information on adverse incidents, though few had been reported in relation to EPIOCs. Alan clarified what could be classified as an incident and urged us to report what could be dismissed as one-off event locally but when put into context nationally could prove to be a more common occurrence. It seems that therapists tend to depend on Rehabilitation Engineers to record adverse incidents. Does this mean that some get missed as the RE is not always on hand?

It is also important that we keep a balanced view on adverse incidents and whilst ensuring that clients are not put at risk, we make every effort to enable our users to get maximum mobility and independence from appropriately prescribed equipment.

Ann Frye from the DETR Mobility Unit spoke on wider mobility and greater freedom of travel on Public transport in relation to the implementation of the Access section of the Disability Discrimination Act. Whilst safety is always an issue, regulations for travelling on buses, trains, trams and in taxis is quite a different ball game. Her slides illustrated how things had progressed over the years, starting with an unbelievable slide of a wheelchair being loaded with a fork lift truck

in Scandinavia and passing on to the current designs for access to public transport. Law now states that all public transport (though not ships and air transport as yet, due to international differences) must provide access for all, including disabled people, though the dates for implementation vary with different modes of travel. This has serious implications for public transport providers who can find that meeting the legal requirements place a heavy burden on their finances. Long distance coaches will need regular stops to provide toilet facilities for wheelchair users as it is simply not practical to have a wheelchair accessible toilet on the coach. As stated by the speaker, this is not popular, as once your load of travellers disembark, it can take some time to herd them all back on board.

The size of space available is also important for the user, as if his chair exceeds the regulation size he may find he cannot get on board. Manufacturers will be asked to specify whether their chairs conform to the allocated space. Whilst there is constant discussion about safety clamps and tie-downs for local authority and school transport, wheelchair users will not be secured in buses, trains or trams, though there will be the use of a bar to separate them in some cases. However, it is felt that, like the general public, many users will simply get on board and sit by the door for ease and speed. Providing access for all is certainly more complicated than it appears at face value, though already many trains and buses, London taxis and new trams provide this facility. Access to stations is a limiting factor but the situation will be well monitored over the next few years to establish how well used the facilities are and what are the limiting factors are.

The final discussion session was introduced by two short presentations. **Jo Kavanagh** from Banstead Mobility Centre provided information on equipment for getting EPIOCs into cars and converted vans and **Rosemary Evans** gave a quick report on a survey of EPIOC users carried out as part of an MSc project. The final discussion was led by Ros Ham and looked at a few of the issues raised earlier in the day.

What Next? The proposal that small groups work to establish consensus on certain aspects of wheelchair assessment and provision to be linked with the PMG Guidelines. The PMG is the most influential group for progress to be made and their Chairman has been approached for his views. If the suggestion is taken up, active participants will be required to be group members.

Patsy Aldersea Merton and Sutton Wheelchair Service Manager

#### Free Paper Abstracts

The Mansfield
Project:
Developing a service to provide
postural care at
night

John and Liz Goldsmith

In 1996 equipment to provide support in any lying position for any size or shape of person became available. The significance of this was recognised by therapists working within a paediatric service in Mansfield, Nottinghamshire. The results of the first two years of widespread use within the service are presented to include:-

The Mansfield Checklist of need for postural care. Provision of a postural care service requires acknowledgement of need and co-operation from all those involved in care for the individual, including management and hands on carers and therefore these factors are expressed in easily understandable terms.

**Developing a Register of people in need of postural care**. A minimum data collection is suggested in order to establish and alert clinical and financial management to the extent of need for postural care within a community.

**Providing training and support for carers**. A training package for carers has been developed and utilised comprising of slide shows and written material. Support strategies have been developed and demonstrated to be effective.

**Assessment procedures** have evolved to include safety considerations and the analysis of destructive and supported postures in prone, sidelying and supine.

**Results of a feedback study** can vassing opinion amongst the families of the first thirty one users to be offered the therapy covered the following topics:-

- 1) Details about the habitual sleeping postures and behaviour of the user
- 2) With the equipment, whether the user slept:- in a straighter or less straight position? better or worse? in more or less pain?
- 3) Whether the user was more relaxed or more tense in the morning
- 4) How long the equipment had been in use? whether a satisfactory position had been established? how long it had taken to come to the position?
- 5) What problems had been experienced and solutions tried.
- 6) Whether the families thought that use of the equipment would be beneficial.

**Short term results indicate benefits**, even for those with established problems and it is considered that accurate therapeutic positioning at night offers an important opportunity to influence body shape and sleep patterns which should be made routinely available to motor impaired individuals from a young age.

John and Liz Goldsmith

Service responsibilities and the needs of the grossly obese wheelchair user: two case studies

Dr Elizabeth White

This paper discusses the mobility needs of the grossly obese wheelchair user, illustrated by two case studies. Consideration is made of moving and handling issues and the duty of care to both wheelchair users and their carers. Clinical reasoning underlying the prescription process is described in terms of service eligibility criteria, and funding implications are discussed.

#### Dr E.A. White

Wheelchair Service Co-ordinator, East Kent Community NHS Trust, Littlebourne Road, Cantebury, CT1 1AZ, Tel: 01227 812393, Fax: 01227 812289

# Who is winning the seating race?

Martin Davy

There is a common belief amongst seating professionals that the glamorous world of motor sport is light years away from the humble wheelchair when it comes to seating. Surely with a limitless budget you can afford the best seat in the house? The reality is that many top racing drivers rely on techniques which are surprisingly familiar, even out-dated, when compared with their 'poorer' relatives in the NHS.

This paper will compare the technologies that are available on each side of the fence from the viewpoint of a manufacturer who serves both sectors. In particular we will consider:

☆ Users
 ☆ Legislation
 ☆ Safety
 ☆ Cost
 ☆ Materials
 ❖ Objectives
 ☆ Duration Of Use
 ☆ Environmental Factors

Assessing outcomes for wheelchair seating has always been a very subjective and unsatisfactory process. By comparison, postural outcomes in motor sport can be more easily quantified. We will demonstrate how the use of timing data and photographic analysis of body movement during cornering has enabled Delichon to improve the performance of its products on the racetrack. By transferring technology across traditional boundaries both drivers and wheelchair users have benefited from these improvements.

As for who might be winning the race? Well you will have to wait until the end to find out ......but the result might just surprise you!

#### M. Davy

Managing Director, Delichon Ltd, Kings Yard, Martin, Fordingbridge SP6 3LB

What is the practical relevance of wheelchair and seating standards to consumers and other stakeholders?

Martin Ferguson-Pell

For nearly twenty years an international initiative has resulted in the development of 22 standards describing the characteristics and performance of wheelchairs. New standards are proposed that relate to seating systems used in conjunction with wheelchairs. How are they developed? Who does the background work and testing of the procedures? Who approves them? What is the practical use of these standards? How do standards influence a client's selection of a wheelchair? How do standards influence purchasing decisions of wheelchair and special seating providers? Is there evidence that standards drive up the quality, safety and reliability of wheelchairs? How can clinical professionals use standards to improve assessment, specification and documentation? All of these issues will be discussed in this presentation.

Wheelchair standards are voluntary and are used to disclose important information about different products. The importance of providing a wide range of wheelchairs, each having different strengths and performance characteristics, is fundamental to

achieving maximum functional independence, comfort, and reduction of secondary medical complications associated with wheelchair use. For example, a client or clinician may wish to know the relative stability of different wheelchairs on inclined surfaces. Although it might seem that maximum stability is highly desirable, this may not be the case for the active wheelchair user who relies upon critical balancing to overcome curbs or to participate in sports. A newly injured person with tetraplegia may on the other hand prefer a wheelchair that is very stable. Standards have been developed to measure the relative stability of different models of wheelchair. Wheelchair manufacturers disclose this information in their technical literature and labelling, allowing accurate comparisons to be made.

Although information characterising wheelchairs consistently across manufacturers is now available for many of the parameters of interest, the integration of this information by wheelchair seating specialists into clinical practice does not appear to have been achieved successfully. Standards that relate to the safety and durability of wheelchairs have also been taken seriously by manufacturers. They have helped to demonstrate that lighter, more versatile and more ergonomically efficient wheelchairs can be more economic to maintain than cheaper depot wheelchairs. As we enter into a new era of standards for wheelchair seating systems, we should learn two important lessons from our first 20 years: simplicity and focus on practical issues is paramount and secondly clinicians need to develop ways to use

this information more effectively. Wheelchair and seating standards can help us serve our clients better, can drive up product quality and value, and help in the design of outcome studies.

#### Martin Ferguson-Pell,

ASPIRE Chair in Disability and Technology, Centre for Disability Research and Innovation, University College London

An investigation into perceived stress levels within the confines of families with a disabled child

Alan McAlpine

**Aims:** This study aimed to determine the general levels of stress in parents with a physically disabled child. In particular it endeavoured to identify the factors causing the stress, those biographical groups most likely to suffer the highest levels of stress and to suggest how the limited resources are best utilised to help and support those individuals most at risk.

**Method:** The population used in the research was the existing caseload of the Rehabilitation Engineering Service. One hundred and seventy four questionnaires were distributed to families with a physically disabled child aged twenty-five years of age or less. The geographical area covered was that of south-west Wales and incorporated both Iechyd Morgannwg and Dyfed Powys Health Authorities. Permission was granted by both the Authorities Research Ethics Committees for the research to take place. A total of ninety-eight completed questionnaires were returned. Six questionnaires from the total number had to be disregarded. This resulted in a total of forty-

one families (44.6%) from the West Glamorgan region (Iechyd Morgannwg Health Authority) and fifty one (55.4%) from the Dyfed Powys Health Authority taking part in this study. The quantitative data collected was analysed using the Statistical Package for Social Sciences (SPSS). Frequencies, cross tabulations and Chi-square significance tests were used, where appropriate, to provide an insight into the possible correlation between two variables.

**Results:** The results indicated that parents caring for a female child experienced more stress than those caring for a male child and those with a child in the 0-7 year old age group found it more difficult to cope than parents with an older child. The analysis also showed that those families living in West Glamorgan had higher stress levels than those in Dyfed. From a possible twenty-two stressors "Concern about your child's future as you grow older", was identified as the most prominent source of stress by all biographical groups with little difference in either West Glamorgan or Dyfed. Parents stated that they had a great deal of difficulty in accessing information outlining resources available to them and that the level of bureaucracy encountered when attempting to secure services caused high levels of stress.

**Conclusion:** It was concluded firstly, that the parents need to be helped to develop coping skills. Secondly, it is imperative that the level and amount of support afforded by the professionals be assessed in accordance with each family's individual needs and accordingly, 'blanket' decisions should not be made.

#### Alan McAlpine

Rehabilitation Engineer, Department of Medical Physics and Clinical Engineering Morriston Hospital Swansea

# Telemedicine: applications to seating and mobility services

Martin Ferguson-Pell

One of the biggest problems we face in the delivery of wheelchair and special seating services in UK is lack of regional harmonisation. Capitated resources, professional skills, philosophies of care and use of assessment tools are all highly variable between regions and districts. From the client's perspective this is inexcusable, and the government is aware that post-code indexed variations in the quality and scope of health care services are unacceptable. Suggested resolutions to this problem include restoration of centrally orchestrated services. The inflexibility and enterprise quenching impact centralisation would have has been one of the factors propping up the *laissez faire*.

The World Wide Web and other new information technologies offer a promising approach to harmonising and augmenting wheelchair and seating services. RehabCentral.com is a new Web-based resource tool to assist with wheelchair and seating assessment in USA that has been developed by Adrienne Falk Bergen and Michael Silverman.

RehabCentral.com offers a wide range of facilities including: Structure assessment strategies Documentation and database management Justification report generator Product information Education and information service

The clinician typically undertakes a clinical assessment, including consultation with the client, family and caregivers in the traditional way. This information is then input to the program and the specifications for the proposed mobility system are developed. Potential products that meet these specifications are then presented to the client and clinician. Once a product has been selected a local distributor is automatically identified and an order can be placed directly on-line. RehabCentral.com have agreed to collaborate with SCAMP in the development of a UK version of RehabCentral.com and beta testing is anticipated early next year.

Rehab Anywhere is a telerehabilitation system developed at University of Pittsburgh in collaboration with Artsco. This system is designed to enable communication of television image, pressure mapping and audio information between specialists at a central station and clinicians working at remote clinics or in the community. Although the video image is a little grainy and frame rates are slower than normal TV, very acceptable results are possible using traditional telephone lines. Alternatively if an ISDN line is installed for about £30 per month, the signal quality and speed can be increased substantially. SCAMP has recently ordered Rehab Anywhere which will allow links to be established between clinics at Stanmore and Central London, and also with the National Neurological Hospital. CDRI will be collaborating with Artsco to make Rehab Anywhere compatible with UK product codes, and will also expand its use into the field of orthotics.

Martin Ferguson-Pell, ASPIRE Chair in Disability and Technology Emma Parry, Clinical Director, SCAMP Centre for Disability Research and Innovation, University College London

#### Invited speaker reports

# What our legal liabilities are

Paul Denton Quantum Developments Paul opened by defining three areas of legal liability;

- ☆ The employee/employer relationship (noting that employees include contractors)
- ☆ Professional liability
- ☆ Negligence

Negligence cases cost some £230-250mn per year, of which only about £30mn is awards to the litigants, the rest being legal fees.

**What, then, is law?** There are various laws; The laws of a game, eg football or golf, and the unwritten social rules of, for instance, queuing. There are the natural laws of physics or mathematics. There are laws of estate (the rules of society).

And what is the point of these laws? freedom equity and democracy, freedom from want, freedom of labour, freedom of speech and the press, freedom of religion, personal freedom (but within the law), freedom of contract, the right of association, the right of property

Paul then considered the employee/employer relationship in more detail, starting with the formal definitions of the employer as the master and the employee as the servant.

The employee has expectations that the employer will find him or her work, will pay appropriate wages and will accept vicarious liability for the employee's actions.

The employer also has expectations; that the employee will show obedience, competence and will act in good faith (ie, will not do the employer harm).

There is also another authority – a super employer – beyond one's immediate employer. That is the Department of Health with its expectations:

☆ Clinical governance

- ☆ Patient's Charter
- ☆ Quality standards

The employee can lawfully refuse to obey:

☆ an unreasonable request or demand

☆ if he or she is not competent

☆ if the action will harm another

☆ an illegal instruction

and has some options for action:

☆ do as he or she is told

☆ negotiate a solution

☆ exercise the right to move and work elsewhere

As professionals we have certain expectations and duties:

- ☆ To act always so as to promote and safeguard the welfare of others.
- **☆** To ensure no action or omission will be detrimental to the interest, welfare or health of patients.
- ☆ To maintain and improve our professional knowledge and competence.
- ☆ To acknowledge any limitations in our knowledge and competence.
- ★ To report to an appropriate authority the circumstances in which safety of patients may be affected.
- ☆ To be aware of health and safety aspects of our work and the workplace.

Finally Paul turned to the area of negligence and liability and defined some principles.

- ☆ There is a duty of care to patients
- ☆ There is a breach if you have failed to exercise your duty of care
- ☆ There has to be injury
- ☆ The effects have to have been foreseeable

Lord Aitken set out the neighbour principle in 1932 in Donaghue versus Stevenson. The reasonable care to avoid acts or omissions which can reasonably be foreseen to harm your neighbour. Your neighbour is any person who is so clearly and directly affected by your acts or omissions that you ought to keep them in mind when considering the effects of those acts and omissions.

Then there is the 'but for' test. The injury would not have happened but for ......

Damages are assessed by a multiplier system in which all body parts are valued. There is a price list. Agreement on damages may then be reached on the court steps or by the court.

In line with the principles of negligence set out above, a defence could be any or all of the following

- ☆ That no duty of care was owed
- ☆ There was no breach of duty
- ☆ There was no injury
- ☆ The event could not be foreseen

There is also the plea of volenti non fit injuria (no wrong is done to one who consents). This covers prior knowledge of the risk, when one cannot sue later eg, bungee jumping, sports and dangerous pastimes.

Negligence actions being within civil law, proof is on the balance of probabilities being greater than 50%. The burden of proof lies with the plaintiff when there is absolutely no doubt about the truth.

The expected level of practitioner competence is that of the reasonable practitioner, what he/she should know and what he/she should be able to do.

The public expectations of the professional are that;

- ☆ Professionals will act professionally
- ☆ Professionals will act always in their best interests
- ☆ Professionals are grown up and able to speak
- ☆ Professionals should be proud of the trust placed in them

Conclusions (or rather, final considerations)

Why do we do it, despite all this! Should we carry on doing it? What is likely to happen if we do?

Actually, the chance of ending up in court is very, very small (despite the increased publicity). Precise documentation is essential and this ties in with later workshops in the conference.

One questioner asked about changes to terms and conditions in contracts of employment. Paul said that one can refuse an instruction if it is not specifically in one's contract. However, the law changed to allow employers to exercise a 90 day notice of change of contract.

In answer to another; action must be brought within 3 years of an alleged act of negligence.

#### Freedom Vs Choice

Barry Cooke Irish Wheelchair Association Barry presented his experiences of freedom vs Choice, starting with a number of examples of every day situations that we take for granted. For instance, the shopping trip to buy clothes. As you'd expect, before you make a purchase you would like to try on the garment, so you ask if you can use the changing rooms...usually no problem. Barry related an occasion when he and a friend asked that very question at a well known high street store. They watched with interest the increasing embarrassment of staff as they realised that the changing rooms were upstairs, there was no lift and clearly there was no way that Barry was going to be able to access the changing rooms in his wheelchair!

Barry also identified problems with the very systems that are put in place to assist the wheelchair user. Parking spaces that are specifically designed with greater space to allow easier wheelchair use are essential, however they are only provided in specific areas. Where is the freedom in being told precisely where to park when really you wish to be able to park anywhere - just as able bodied drivers can! Where is the free-

dom in booking a holiday when the destination and resort of your choice doesn't have wheelchair access? Limited access to public transport (how many 'low-floor' buses have you been on recently??) mean that taxies are an essential key to freedom of movement for wheelchair users. You can imagine how pleased Barry would have been when he discovered a taxi company who marketed themselves on being registered as wheelchair 'friendly', infact they were receiving financial benefits for being thus equipped. However booking one of these cabs proved virtually impossible. Whenever Barry rang to book a cab he was told none were available - too busy transporting able bodied customers!

Barry gave an informative and entertaining presentation on the limitations of freedom and choice of wheelchair users, and also touched on the inequality in the choice of provision across different health authorities. He gave a timely reminder that wheelchair users are fully capable of improvising and overcoming difficult circumstances. On hearing that disabled people were entitled to a 43% discount on new cars it was rumoured that cars had been bought... and then sold on at a profit!

### Effecting changes in the musculoskeletal system with postural management programmes

Terri Poutney
E. Green, R. Nelham & C.
Mulcahy, Chailey Heritage
Clinical Services

Changes can work throughout life to detrimental or improved effect. Muscle and bone is adaptable and change in response is influenced by:-

- 1) Growth
- 2) Use or disuse
- 3) Function
- 4) Nutrition
- 5) Bio-chemical force.

#### Muscle structure:

**Slow twitch:** sustained by low intensity activity, these fibres develop with growth slow or abnormal growth gives rise to less slow twitch fibres.

**Fast twitch:** gives rapid power movement - they grow rapidly when used and are present at birth.

Muscle lengthening follows bone growth, however short muscle can be failure of the muscle to lengthen rather than true shortening. An imbalance of muscle activity leads to abnoimal movement patterns and immobility and disuse leads to muscle atrophy.

Effects of length changes in muscle are summarised below:

Shortened muscle will:

- 1 Lose sarcomeres
- 2 Have a shorter fibre length
- 3 Develop connective tissue restrictions
- 4 Becomes strong in the short range

Lengthened muscle will:

- 1 Gain sarcomeres
- 2 Have a longer fibre length
- 3 Have stretched connective tissue
- 4 Become weak in mid and inner range.

Muscle shortening requires strategies which lengthen muscle.

#### Bone structure

Shape is dependent on function and can be changed by faulty loading by muscles. The types of forces acting on bone are:-

- 1 Compression
- 2 Shear
- 3 Torsion
- 4 Bending
- 5 Tension

The effects of forces during development on the growth plates:

- 1 Intermittent compression stimulates growth which is normal. Increased compression on one side leads to a decrease in growth on one side.
- 2 Causes change of direction of growth.
- 3 Torsion.

It is vital to position according to chronological age not developmental age, i.e. at 3 months provide symmetrical support, seating at 8 months and standing at 12 months.

#### Implications for therapists and RE's

The following need consideration.

- 1 Timing of provision
- 2 Symmetrical forces
- 3 Correct body alignment
- 4 Variety of positions
- 5 Maintenance of muscle length
- 6 Load bearing
- 7 Movement

#### Workshop Reports

### **Appropriate** Record Keeping

Liz White

Four working parties addressed the documentation requirements of client group, therapists, rehabilitation engineers and for service related records. Each party had a similarly structured set of five questions to answer and present to the workshop.

#### CLIENT GROUP

1. What documentation should be given to wheelchair users by the wheelchair service or commercial sector.

A comprehensive list was produced under the following sub-headings:

a) Pre-assessment; an expectation booklet or letter; what happens next, waiting times, etc.

Voucher information

EPIOCs; questionnaire, GP consent, waiting times.

b) Clinic or dv appointment; the working party said that this was documented but not given to the client. (Recorder's note. I think this is probably so for most wheelchair services. Others such as most or all prosthetic services and many specialist seating and rehab centres issue, for example, a care plan to client, carers, referrer, GP, etc, detailing clinical and technical matters, and recommendations and agreed plan.)

#### (c) At delivery:

Useful contact numbers

Terms and conditions of supply

User manual

Copy of check list User Group information EPIOC insurance information

#### 2. In what format should this be provided

Mainly covered above, ie booklets, letters, individual sheets.

(Recorder's note. A users and carers information folder with pockets to hold leaflets, etc, is useful. There's quite a lot of paper referred to above!)

3 Should the service record the information that is given to clients - if so, why and how should this be undertaken

This was not directly answered except that under the pre-assessment information sub-heading a rubber stamp was proposed to record client and referrer informed.

(Recorder's note. Clearly the answer to the main question is Yes. As to why and how, well, it is a tenet at law, which you should also apply to your internal complaints investigations, that if it wasn't written it didn't happen. Therefore, tell them, record that you told them, preferably give it in writing, and get them to sign for it. That should just about cover it.)

4 What documentation does the service require from clients and/or carers

Signatures mainly; for receipt of wheelchair and all associated kit and on terms and conditions form. Notification of a change of address is rather useful.

5 Define three statements that summarise the key points of documentation related to wheelchair service users

- ☆ It should be informative
- ☆ It should record trials and decision
- ☆ There should be a signed agreement

#### THERAPISTS

- 1 What documentation should therapists be recording, and in what format
- ☆ Client expectations
- ☆ The clinical assessment (on formal assessment form)
- ☆ The outcome of any contact
- ☆ The plan of action
- 2 How should information received by phone be recorded
- ☆ Record the details of the conversation, and who phoned
- Record any action and plan resulting from the call
- 3 What documentation should be given by the therapist to the wheelchair user. Should this be recorded, if so, how and why

In answer to the first part only eligibility criteria were mentioned (eg, for EPICs, EPIOCs, high performance chairs and vouchers). Yes, whatever it is should be recorded in the patient's notes.

4 What is the therapist's role in developing documentation relating to new developments

#### Please write to Post Bag if you have a view

This was left un-answered which was surprising,

- 5 Define three statements that summarise the key points of documentation related to therapists
- ☆ Thorough including client expectations
- ☆ Concise
- ☆ Accessible to clinician and client alike

#### REHABILITATION ENGINEERS

- 1 What documentation should REs be recording
- ☆ REs should be writing in the clinic notes
- ☆ Adverse Incident Reports (Very interesting. I do not think this would be top of the list for any other group in the NHS)
- ☆ Pre-delivery inspection

- ☆ Service history
- ☆ Visit reports (repair contractor)
- ☆ Work sheets (ie, mods)
- ☆ Environmental reports (for powered wheelchairs)
- ☆ Handover documents (for powered wheelchairs)

#### 2 In what format

Either hard copy or electronic whether for patient's records or equipment history

3 Should records of clinics and dvs be different

No difference.

- 4 What documentation should the RE be initiating
- ☆ Detailed drawings/sketches
- ☆ Product information
- ☆ Clinical use guidelines
- ☆ Risk assessments
- 5 Define three statements that summarise the key points of documentation related to rehabilitation engineers
- ☆ Record of technical advice given
- ☆ Record of action taken
- ☆ Based on approved good working practice (reference Device Bulletin 9801)

#### SERVICE-RELATED DOCUMENTATION

- 1 What documentation is required by the wheelchair service
- ☆ Referral from whom? self, GP, therapist, detailed and complete
- ☆ Prescriptions
- ☆ Actions
- ☆ Orders

# Any service co-ordinators like to add to this, write to Post Bag

#### 2 What format should this be received

The simple answer to what format was 'uniform', which is, I think, a valid answer. One does see everything from nicely structured pro forma to scribbles on reporters notebook pages and worse.

There was a call for catalogues on disc and uniform

product codes. (This means, presumably, nationally standardised descriptive codes. Such things can get rather unwieldy – imagine the old Carters codes expanded to cover all possible options on all wheelchairs!)

- 3 How should documentation be recorded and
- 4 How should client data be stored to be most readily accessible to clinicians, managers and clerical staff

Both seemed to be covered by

- ☆IT dynamic
- ☆writ large on the flip chart
- 5 Define three statements that summarise the key points of documentation related to service providers
- ☆ Current
- ☆ Accessible
- ☆ Clinical notes

In summary, taken as a whole the workshop covered many aspects of record keeping for a wheelchair service. Given time, I am sure anybody present could have got down all the right answers, but even small groups can so easily stray from the point and some of these workshops were very crowded. This one had 59 participants in the first session, though only 20 in the second.

# Access to Education. Clinical v Educational needs.

Ann Evans and Terry Poutney This workshop was well attended and led by Anne Evans, an educationalist responsible for children with special needs (physical) in education with Terry Pountney, research physiotherapist from Chailey Heritage.

Having identified the areas that delegates wished to cover, smaller groups were formed to

address the problems raised in 3 case studies provided by the workshop leaders. These related to:

- ☆ poor inter-agency communication
- delayed communication affecting appropriate intervention or equipment provision

- wasted resources due to duplication of provision
- ☆ difficulty in agreeing responsibility for funding and subsequent failure to provide in some cases

The case studies clearly illustrated the complexity of some of the problems being experienced by families coping with a disabled child.

Apart from the issues of communication and funding, transport difficulties were discussed. An example given related to requests by education for provision of headrests on wheelchairs when a headrest was not identified as being required for posture or mobility. Services varied in their response to this type of request.

Concern was also raised regarding the problems identified in one case history when a student transferred from the paediatric to the adult services.

There were no easy answers to any of these difficulties which are seen on a daily basis, though there was an opportunity to discuss how different services tackled some of the issues. Anne Evans was unaware of the problems relating to wheelchair transport issues and pointed out how progress could be made by linking together on more occasions such as the PMG conference.

Funding, safety in transport and transferring to adult services are on-going problems for all working with children using wheelchairs. Good communication at local level can ease the situation but a concerted effort is required to establish national agreements. Paul Denham, the key speaker at the conference had advised delegates to lobby their MPs by attending local surgeries. This needs to be done in a constructive way in order to progress - perhaps the PMG committee should consider providing guidance and taking a lead in this matter?



# Taking and Managing clinical risk

S Fielden and D Harrison

The workshop started with a presentation by Simon Fielden of a few overheads which dealt with some of the basics of risk management. Most basic of all; what is clinical risk? It is the risk associated with actions planned for the service user.

There is nothing new about this. We've always practised risk assessment

as part of our deliberations to minimise risk to the user, so why manage it? Three reasons were suggested:

- ☆ to avoid litigation
- ☆ to comply with the Medical Devices Regulations
- ☆ it may result in alternative equipment being issued
  which is equally beneficial to the user but carries a
  lower risk

Some terms used in the risk management business were defined:

- A hazard is a potential source of harm and may be an event, a situation or a piece of equipment.
- ☆ Risk analysis indicates the likelihood of a hazard actually causing harm.
- ☆ Risk assessment is, as above, our consideration of whether a risk is acceptable.
- Risk management describes our action in controlling or reducing the risk indicated by the assessment.

Next came the major steps in risk management:

- A Identify all the activities, processes and products which result in increased risk for the user.
- ☆ Identify the hazards.
- ☆ Estimate the risk associated with each hazard.
- ☆ Are the risks acceptable or reducible?

The whole idea is to balance the needs of the user against an acceptable level of clinical risk. Hopefully, the process will be accepted as a positive step leading to more detailed and better considered assessment and greater benefits to the management of risk.

The attendees split into working groups to apply the principles to cases suggested from the floor. As there were two workshop sessions, there were, of course, six

topics covered. The very high attendance at these workshops resulted in more than three groups in each session so that some addressed the same problems. Below is a brief distillation of the deliberations around each topic.

# 1 Provision of an EPIOC to an 18-month old child with spinal muscular atrophy

The child is bright and has achieved the normal developmental milestones. Comet with Gill seat issued at 21 months.

#### Hazards:

- Poor trunk control
- Doing harm to self or to others through poor driving skills
- Seat is detached for use in vehicular transport

#### Risk management:

- Full support, eg, by Snug Seat, full harness
- Programmable control box tuned to lowest settings
- Parents have on/off control
- Supervised training
- Supervised use
- Limit to indoor use
- Train carers in correct assembly of seat to wheelchair

#### 2 Floppy child in transport

#### Hazards

Neck or head injury through being insufficiently supported

#### Risk management

- Provide MSI on Shadow wheelbase to meet postural control needs
- Follow manufacturers guidelines for interfacing the MSI onto wheelbase

#### Risk/benefit analysis

• Risk of using MSI in transport is less than that from not using it

# 3 Provision of a non-approved wheelchair/power pack combination

#### Hazards

- Frame strength; rigid or folding? risk of failure. This was seen as a high risk factor
- Compatibility; direct attachment or welded fixtures.
   Low risk associated with method of attachment

- Weight limit; medium risk hazard, is device powerful enough?
- Stability; a low risk hazard
- Use environment; carers' walking range? use on hills, braking? High associated risk

The group considered that there was a high risk associated with CE marking. Perhaps they meant from the point of view of compatibility, invalidation of warranty and legal risk to the issuing Trust.

#### Risk management

- Is the particular wheelchair available as a powered version? (This is not always an admissible option as for many it is the transportability of the add on system which is most useful.)
- Manual brakes were suggested to deal with the problem of stopping on hills.
- Carer and user consultation and training (to include real road tests).
- 4 Client in MSI on 9L (non-crash tested seating system/interface/ wheelchair)

#### **Benefits**

- There is a postural benefit to the client who remains in supportive seating during transportation.
- There is a quality of life benefit from the reduced manual handling (which is an inflicted indignity) and because of the time saved as a result.
- The carers also benefit from the reduced manual handling.

**Risks** (resulting from an impact or vigorous braking or cornering)

- MSI could detach from chassis high risk
- Wheelchair could detach from tie down system in the vehicle – low risk
- Equipment may come loose and injure other passengers moderate risk
- Risk of client submarining out of seat high risk
- Whiplash injury if headrest not used

#### Risk management

- Is there an alternative?
- Is there a crash-tested alternative?
- Reduce number of journeys (Reporters note: Not always practical and may reduce quality of life)
- Make sure vehicle is suitable (meaning suitably equipped?)

- Staff training
- Consultation with other professionals
- Equipment maintenance
- Fit correct harness and restraint systems
- Risk assessment travels with client

## 5 Overweight gentleman wants lightweight/active user chair

This gentleman is a full-time chair user. As he was over the weight limit for an active user chair he was given a heavy duty 8L type. The chair was more than two years old and was wearing out. Client was very, very unhappy. He also had a drinking problem.

Risks: associated with active user chair

- Chair breaks causing further injury high risk
- Brakes become ineffective? low risk
- Chair possibly too narrow tissue viability low risk
- Stability risk of injury when drunk

Risks: associated with changing chair

- Increase in tone with effort of self-propelling high risk
- Potential secondary injury from self-propelling, eg, to shoulders – high risk
- High risk of injury to wife who loads chair into car
- Threatening behaviour from patient high risk to staff

#### Risk management

- Make enquiries to find chair meeting all needs
- Change chair
- Issue voucher to assist change if needed
- Ask GP for referral to dietician
- Give both chairs to meet different indoor and outdoor needs
- Do not see patient alone
- Involve manager (Reporters note: I hope this does not mean that the service manager is only seen as a last resort)

Following this Simon outlined the Birmingham approach which is that a detailed and recorded assessment is made and if:

- the equipment is to be used outside of its intended purpose
- ☆ a local adaptation is to be used
- two or more items are to be used with manufacturers agreement on compatibility
- ☆ stability is an issue

then a risk/benefit analysis is made. Benefits must be real and very viable.

Risks must be quantified in terms of likelihood and severity. (Previous experience plays an important part here.) Unacceptable risks must be reduced, and if that is not possible, refer to your Trust risk management team.

Above all, do not lose touch with reality.

### New standards for wheelchair cushions

Ray Hodgkinson and Robin Luff

This 'workshop' was more of a reporting and information session and a call for participation than a traditional workshop. Ray Hodgkinson, assisted by Robin Luff, introduced the need and history to date of the new standards in wheelchair seating.

There has been a proliferation of cushions available in the marketplace

over the last 10 years. At present there are no agreed methods of performance assessment, and as a result there is no reliable information for prescribers. As a result cushions are described very subjectively by manufacturers as 'low risk', 'high risk', 'therapeutic', 'comfort', etc. There is no basis for these descriptions, and what is suitable for one group of users may not be appropriate for another.

There is also a discrepancy in what items are called, and there are no set methods for quantifying diagnostic terms such as pelvic obliquity. Is the lump in the middle of the seat a pommel or an adduction pad or a what? Is the leg rest really a leg rest? Usually it is a hanger bracket on which the leg does not rest at all. What is the best term to use to describe the person in the wheel-chair?

It was for this reason that the Posture and Seating Section of the BHTA pushed for ANSI/RESNA in the USA to put forward a proposal that there should be an ISO standard for cushions and seating materials. ANSI/RESNA already has a standards section working on wheelchair standards, and had been very proactive in the 22 parts of ISO7176, the international wheelchair standards. They therefore proposed the new standard as

an extension of their current activities, to be divided into 4 parts:

- Part 1. Terms and Definitions
- Part 2. Pressure Management Devices
- Part 3. Postural Support Devices
- Part 4. Transportation

These proposals were accepted by ISO in November 1998, with the first 3 parts to be the responsibility of an new Working Group, WG11, under the leadership of Dr Geoff Bardsley from Dundee. The fourth part went to WG6 to look after. (The ISO7176 wheelchair standards are run by WG1.) The first WG11 meeting took place at the International Seating Symposium in Orlando in February 1999. The Committee Draft is due to be submitted by the end of 2000 for circulation around each country for amendments and votes, with the final standard due to be in place by the end of 2002.

The representatives on WG11 are experts nominated by each country's standards institute – in the UK, by BSI; in the USA, by ANSI; etc. Other interested individuals are also welcome to attend. At the workshop, Ray encouraged attendees to sign up to participate in each of the standards as the occasion arose. The best way to keep up to date with the progress of the standards and the international discussions around them is to subscribe to the relevant ones of the three listserves on the internet (contact Ray Hodgkinson (01732 458868) for the correct address to subscribe), or it is possible to download the current drafts from the website (Error! Bookmark not defined. You will need an Acrobat reader to access them since they are stored as .pdf files, but this can also be downloaded from this site.

At present you are encouraged to use either the internet route to channel your participation, or through Barend ter Haar (tel/fax 01223 882105) for the Terms and Definitions section, Professor Martin Ferguson-Pell at Stanmore for the Pressure Management Devices section, and Ray Hodgkinson for the Postural Support Devices section.

At the meeting in Orlando, it was agreed that Part 2 should be called Tissue Integrity Devices to take away the emphasis from just Pressure Management. However, the work and the initial round of standards will have to concentrate on existing tests and technology. There will not be time to develop new techniques within the timescale of the standard. Notwithstanding,

there will be an appendix with markers of further areas which need to be developed. The standards are routinely reviewed on a 5 year cycle, and opportunities to bring in other measurement parameters will occur in that period.

At the end of these procedures, hopefully these new standards will help to:

- ☆ Reduce trade barriers
- ☆ Ensure minimum safety and quality standards
- ☆ Stimulate appropriate design and development
- ☆ Inform on prescription and purchasing choices
- ☆ Aid communication and collaboration

There are also the prospects that the work being carried out on the rather specialist areas of wheelchair seating will be extrapolated into broader areas of rehab seating and into other patient support surfaces, such as mattresses.

Footnote. Amongst the proposals accepted so far include the person in the chair to be known as the occupant. The primary support surfaces are to be called supports. Thus, the piece behind the occupant is to be the Back Support (not the 'back', nor the 'back rest'). The piece under the arm is the Arm Support (not arm rest).

### Professional standards of practice.

**Christine Turner** and Phil Swann

Looking at the large number of delegates who attended this workshop, it seems clear that many are seeking guidance on setting and measuring standards in order to improve the service to people with postural and mobility problems.

The workshop leaders, Christine Turner an Occupational Therapist working for Invacare and

Phil Swann, Clinical Engineer from the Stanmore regional seating team, had prepared 3 issues to be addressed in smaller groups.

The starting point was to establish the range of professionals involved in postural and mobility services, the variety of skills and knowledge they brought to the service and the professional groups in existence who set standards and represented their interests. In addition to

this, participants were asked to consider whether they had received sufficient training for their present position and what training they felt they would benefit from in the future. It was apparent that the Rehabilitation Engineers had the most structured post-graduate training programme organised by CORE, due mainly to the funding that had been invested in these courses by the DSA. Other professionals obtained their on-going training in an ad hoc way either locally, through conferences such as the PMG or courses organised by commercial firms advertising their products. None, if any of these have formal recognition or meet set standards resulting in accreditation for participants. One therapist recommended the course run at the Mary Marlborough Centre, Oxford, though it is known that this is currently awaiting accreditation and therefore not at present being held.

Reference was also made to Greenwich University who have recently validated the first of five modules relating to wheelchair prescription and provision. This course will shortly be available and provide an opportunity for accreditation to therapists and others meeting the entrance criteria.

During this workshop, and also in some of the plenary sessions, delegates were reminded that their professional bodies already provide standards relating to their work generally and have some responsibility to ensure their members maintain an acceptable standard of practice. Whilst some professionals already have a formal CPD structure set by their professional body, others such as the therapists are still being agreed. It was pointed out that Rehabilitation Engineers will shortly have a CPD programme that will be monitored by the IPEM.

It is clear that whilst the absence of suitable courses is part of the problem, the main difficulty is lack of support and resources (time and money) from managers and employers to allow attendance on training days and so maintain high professional standards.

Inferior chairs, coupled with incorrect ways in which we sit, cause more industrial and personal injuries than autos, hand guns, and factory machinery combined. Dr Ronald Harwin & Colin Haynes Healty

#### **PMG NEWS**

#### OBITUARY Chris Bar Ph.D.

Chris died in March this year after being found collapsed in a gym in his adopted country. the USA. He was an active researcher and developer in the fields of mobility and posture and it is appropriate that his life and contributions in working with people with disability are recognised in the Bulletin of the PMG.

Chris moved to the USA in 1996 to take up a pivotal role with Roho in developing innovative systems, reflecting his interest throughout his professional life in pressure relief: Before this he had worked at the Artificial Limb and Appliance Centre at Rookwood in Wales where he was held in the highest esteem by colleagues and patients alike. His first contact with the Centre was as a student when a project based on pressure relieving cushions in the Spinal Injuries Unit carving foam cushions - led to an ever greater involvement with services for people with disability.

His undergraduate training was in engineering at the University of Wales, Cardiff and after graduation went to work at Rookwood within Rehabilitation Engineering. He subsequently completed a major P.h.D programme into the prevention of pressure sores leading to the award Doctor of Philosophy. His interest, enthusiasm, dedication and outstanding abilities were recognised and he became head of rehabilitation engineering and manager of wheelchair and prosthetic services. He was the source of continual innovation; amongst his achievements were the Celt wheelchair range, the Pioneer, the Camp-Rockwood modular seat and the seating simulator. Chris always had an active interest in information technology, an interest he pursued with Roho. Many will remember his very early demonstrations of computer control audio-visual presentations whilst lecturing. He would be delighted to see the almost universal adoption of computerised presentations in current meetings. Chris was a great supporter of the Posture and Mobility Group and regularly attended the annual conferences. The quality and content of his presentations were always of the highest standard and he was a free paper prize winner. He frequently and convincingly stated the need for measurement in posture and recognised the importance of appropriate research long before evidence based prac-



tice became a guiding principle. He will be sorely missed. He is survived by his wife, Melanie, to whom our condolences must be directed.

He is remembered by his colleagues at Rookwood in terms of two driving forces:

#### do it better and do it faster.

Widespread adoption of this philosphy might be a fitting memorial to the life and work of Chris Bar.

#### Robin Luff

# Annual General Meeting at Glamorgan '99 12:00 Tuesday 13th April 1999

#### 99 AGM.1 Membership

More than 30 members present

#### 99 AGM.2 Apologies for Absence

Emma Parry, Dr Marks

#### 99 AGM.3 Minutes of previous meeting

Proposed Christine Turner, Seconded Sandy Clarke, agreed *nem con*.

#### 99 AGM.4 Matters arising

None.

#### 99 AGM.5 Chairman's report

See page 29.

#### 99 AGM.6 Treasurer's Report

See page 28. Proposed by Libby Bradshaw, seconded by Roy Nelham.

#### 99 AGM.7 Elections to committee

5 members to stand down. 4 willing to stand again. Paul Dryer unable to stand again. No nominations received to committee. All four members standing again were re-elected en bloc. Proposed by Dr Harish Nirula, seconded by Liz White. Possibility of co-opting member to committee from NW area to help with 2000 conference.

Request from Ross Ham noted for a list of committee members and the dates they are due to resign, to be published in the newsletter so that potential new members can be recruited in time.

#### 99 AGM.8 Year 2000 meeting

Confirmed as 10/11 April 2000 at Llandudno. Robin Luff mentioned that special interest groups are to be invited to this meeting. Terri Poutney has contact with APCP - she will report back to Julia Cunningham. Liz White will contact OT group re Learning Difficulties. Jacqie Donaldson will contact clinical interest group in orthopaedic prosthetics. Lone Rose asked about inviting user groups. Robin Luff responded by asking for constructive suggestions as to how to involve user groups in a conference.

#### 99 AGM.9 Role of PMG into Millennium

9/1 Baarend ter-Haar suggested that the newsletter is changed to become professional journal - he has contacts whereby journal could be published. The journal would then go worldwide. Library subscriptions and advertising are a plus. David Thornberry asked if newsletter items could be mixed with professional journal or should it be two separate items. Barend responded that newsletter items could take the form of a loose sheet in the journal. Matter to be further considered by committee.

**9/2** Request from floor for a published list of courses. Response: Dave Calder will develop appropriate web site.

9/3 Paul Richardson asked about PMG links with RESNA. Robin Luff responded that RESNA is a very engineer orientated group but that as 40% of PMG membership are engineers, the committee will undertake links on behalf of the floor. Paul Richardson feels that the group is very multi discipline. He would like to see better links with Europe and feels that a PMG/RESNA link would help this.

**9/4** Pru Cartwright is concerned about changes in the NHS. Asks that the PMG as a group state that to split specialist services from other wheelchair services will be detrimental to wheelchair services generally.

Robin Luff replied that wheelchair services may devolve even further causing problems and that PMG need to state that whatever happens there needs to be a clear continuing relationship between wheelchair services and specialist centres.

9/5 Roy Nelham asked if we should be vocal re changes in funding now. Advise budget holders in use of monies.

#### 99 AGM.10 Any Other Business

None.

#### 98AGM.11 Date, time and venue of next meeting

Llandudno 11th April 2000

Robin Luff extended his thanks to the membership.

# FINANCIAL STATEMENT FOR THE POSTURE AND MOBILITY GROUP OF ENGLAND AND WALES

#### 1 January 1998 - 31 December 1998

Income	01 2 000m501 2>>0	
Subscriptions		
Prepaid in 1997 (Carried Forward)	£ 28	35
Paid in 1998	£ 224	15
Prepaid for 1999	£ 315	
Total 1998		£ 2530
Contribution from Dundee 1997		£ 5500
Hull Conference 1998		
Income	£ 479	74
Less Costs	£ 407	57
Surplus		£ 7217
Bank Interest		£ 447
TOTAL		£ 15694
Evmonditure		
Expenditure Administration		£ 51
Newsletter and Guidelines		£ 5362
Committee expenses		£ 1592
Accountancy (1997)		£ 1392
Inland Revenue		£ 12
illiand Revenue		2 12
TOTAL		£ 7158
Surplus of income over Expenditure		£ 8446
Available funds at 31 December 1998		
Premium Business Account	£12396.59	
Treasurer Account	£ 5096.34	
TOTAL	£ 17492.93	

The PMG committee are pleased to announce that all members attending the 2000 conference at Llandudno will receive a yet another book voucher as part of the PMG's commitment to education.

#### Congratulations:

**Dr Martin Ferguson-Pell** winner of the 1999 Free Paper competition. Martin presented a paper on Telemedicine and its applications to seating and mobility services, see page 14. Read the abstract and ask yourself how you can use this new technology to improve service delivery.

# POSTURE AND MOBILITY GROUP FOR ENGLAND AND WALES CHAIRMAN'S REPORT TO THE ANNUAL GENERAL MEETING APRIL 13 1999 THE GLAMORGAN BUSINESS CENTRE UNIVERSITY OF GLAMORGAN

#### INTRODUCTION

With great pleasure I report, as your Chairman, on the activities of your professional body, the Posture and Mobility Group of England and Wales for the 1998-99 year. There is however some sadness in this event since it also marks my time to standing down as your Chairman. It is pleasing nonetheless to be giving this report at yet another "sell-out" Annual Conference. I am delighted that so many could attend and sorry that we were not able to welcome all the possible delegates to this Conference. I shall return to this when I consider future conference plans.

#### THE COMMITTEE

This represents the first full year of working of the new Committee as elected at the last Annual General Meeting. The current membership represents therapy, engineering, medical and commercial viewpoints and has worked in a most constructive fashion to promote the PMG. On behalf of you all I give them many thanks for the splendid and unstinting effort they have made as your representatives. It is instructive to realise that this is entirely unpaid and usually requires allocation of precious annual or study leave time. It is therefore appropriate that I also record my own very real thanks for their efforts.

Without this volunteer committee, the PMG would be a very different animal. At this AGM five members will have completed their periods of office as determined by the Constitution - myself, David Thornberry, Patsy Aldersea, Rene Parison and Paul Dryer. Paul does not wish to stand again at this AGM - something to do with in-house wheelchair maintenance contracts - and I pass to him special thanks for his contribution. In accordance with PMG practice, the newly elected Committee will elect the Chairman after the AGM.

#### **MEMBERSHIP**

Paid members have decreased in number in the last year but numbers are rapidly picking up again. Barend ter Haar has worked particularly hard since taking on the task of membership secretary to sort out the true membership position and the associated membership and mailing databases. He has equally struggled to deal with the complexities of membership fees following my abortive attempt to rationalise this at the last AGM! That we have any clear idea of who the membership is, where they are and how their membership fees are paid

is almost entirely the results of his hard work and I thank him on behalf of us all.

The PMG is no more than the combined talents of its membership. I remind you again that it is in all our interests to expand the membership of the Group. Individuals working in the mobility and posture fields are themselves rather too mobile and therefore difficult to identify year on year. Please let the Membership Secretary know of any changes as soon as possible even if it only comes to you as gossip. We can always check the source material.

#### THE CONSTITUTION

This is a quiet year for the constitution of the Groupeveryone may breathe a sigh of relief. This is due in small part to the tireless work put in by Roy Nelham who comes well briefed from his experience with the ISPO (UK Branch).

#### **EDUCATION**

You will have seen the developments in training in our specialist field described in the current Newsletter. The PMG must be seen to support this initiative and will work to promote it. Appropriate CPD/CME credit will be obtained for this Conference. It is our intention to establish with the relevant specialist bodies that our conferences should have recurrent, rather than individual recognition. A subsidy for the purchase of professional publications will again feature this year and I trust you will all make good use of this opportunity. We have already had some discussions about the regular offer of bursaries to attend our conferences; this has the student engineers in mind particularly but could apply to anyone fulfilling the as yet undetermined criteria.

#### **CONFERENCES**

The venue for the 2000 Conference has already been set. This will be in Llandudno, North Wales. This will provide a large venue with excellent and flexible resources right on the sea font. We hope to involve the British Paediatric Association and a number of therapy special interest groups in this Conference. The 2001 Conference is under discussion and there is a plan to hold a combined conference with the Scottish Wheelchair and Seating Group. Some discussion has taken place; the venue will be "somewhere up north". Your Annual Conference is the largest single activity of the Group each year and the source of much of our

income. The continued financial stability of the Group and its ability to extend its activities depend on the continued success of conferences. Your support and involvement is thus essential and I encourage you to become and remain involved.

#### **POSTURE AND MOBILITY - The Newsletter**

This continues to go from strength to strength under the adventurous guidance of its editorial committee. This dedicated band - Phil Swann. Patsy Aldersea. David Calder and Julia Cunningham (aka Meetings Secretary) - deserve our whole hearted thanks. Your Committee is conscious of the fact however that the Newsletter represents a considerable burden to our financial resources. The better the content, the better value for your money. I encourage you all to contribute, from the most learned of articles to the most outrageous of jokes. I am not so sure about the photographs however

Your Committee has discussed possible developments of the Newsletter to reflect its current excellence. You will note that the front page has changed in the latest edition, the header now, being "Posture and Mobility". It may be possible in future to arrange for its issue through a publishing house which would then provide the status of a reference journal. The business case for this is not yet fully established.

#### NATIONAL AND INTERNATIONAL ACTIVITY

The PMG represents the only multi-professional body with a special interest in wheelchairs and posture. It is appropriate therefore that we are represented on the relevant national bodies. I am pleased to say that the PMG has been invited to join the BSI Working Party on wheelchairs and seating. Furthermore, two of the Committee have been appointed as expert representatives to the ISO working parties. This is important work in which the entire membership can share since the way in which both BSI and ISO operate is by widespread consultation.

#### THE FUTURE

Last year the excellent discussion led by Dr. Linda Marks, who unfortunately cannot be with us at this Conference, covered amongst other areas the importance of comprehensive posture programmes and the interservice working this would necessitate. This has been taken on in the correspondence in "Posture and Mobility". raising the question of a future strategy for the PMG. Establishing consensus about best practice and making use of such clinical evidence as there is in our field will be essential for the future growth of our special interests - and therefore the benefit of the population with which we work. I end my report by paraphrasing Lord Steele: at a time when the government has imposed a framework to ensure health care provi-

sion adheres to evidence based clinical practice, I say "Go Home - and prepare for governance" - but not before the end of the Conference.

#### Robin Luff FRCS FRCP

A short committee meeting followed the close of the 99 PMG Glamorgan conference to elect committee members to office. Your new Chairman, Roy Nelham, was unanimously



voted in and accepted this honourable position.

Barend ter-Haar will continue as treasurer and Julia Cunningham as secretary.





## Post Bag





# THE MOVEMENT FOR NON-MOBILE CHILDREN Can we hold hands and sing the same tune?

#### Introduction

Whizz-Kidz was established in 1990 when the Chief Executive Michael Dixon and a Trustee Dr Ricky Richardson, ran the London Marathon and raised funds for a powered wheelchair for a young girl in Norfolk. The charity has grown each year with funding coming from a variety of sources including trusts, businesses, events, community groups, schools and universities. The Millennium sees the 10th Birthday of Whizz-Kidz and over the last decade many changes have taken place, notably the size of the income generated, changes in statutory provision and also the growth in the network of Whizz-Kidz mobility therapists throughout the UK (except at present, Northern Ireland) from one to 10.

#### The current situation:

With these changes, to name but a few, the charity continues to review its policy regarding provision and how it can continue to improve the 'lot' of the disabled child in the UK. Ten years ago the EPIOC Scheme had not been launched and the need for powered wheelchairs for children was great. Some areas were providing tricycles in 1990, a continuation in the provision from the DHSS and DSA days. Specialised seating for the severely disabled was in its infancy with matrix, foam and wood and moulded inserts being the norm. Today EPIOC provision is well established in most wheelchair services. Tricycles are rarely (if at all) provided by statutory authorities and the assessment and prescription of various items of specialised seating, both off the shelf and custom made, is provided more objectively and effectively. Also staff are more knowledgeable on the topics of mobility for the disabled population, assessment, postural management, specialised seating and cost effectiveness of equipment provision.

#### The present:

So where does that put Whizz-Kidz? Well we continue

to be called on to provide mobility equipment for children with disabilities whose needs the statutory providers cannot meet, or who do not meet the local eligibility criteria. The average cost of the powered wheelchair Whizz-Kidz provides is, for example, £3000. (The average cost of the NHS EPIOC wheelchair is currently £ 1500.) Are we therefore being asked to provide more sophisticated devices that the NHS cannot fund. Are we improving the quality of life of those borderline cases, or are we simply duplicating provision? Who else provides tricycles that can carry the rider and a disabled child? Where does a child obtain a sports chair to develop their social skills and social integration? Do you know of a statutory provider who funds such equipment? Is the NHS measuring quality of life, total care costs or simply touching the tip of the iceberg'? Or are we the easy touch?

#### The future:

The charity now wishes to more actively collaborative with the statutory providers to ensure that further duplication does not occur and the funds are targeted to those children who have the greatest needs and will benefit the most from the equipment provided. At the October National Wheelchair Managers meeting in Bristol, the desire for collaboration between Whizz-Kidz and the NHS was raised and I hope this message will filter down to the services and be receptively received. This year, we have joint funded with NHS wheelchair services, a number of items, but we are looking to increase this level of joint working and funding, perhaps with the voucher scheme (which is being used for EPIOCs by some services), perhaps simply with top up funding. The time is 'right'. The government talks of, 'joined up working', 'partnerships' and collaboration between different agencies (statutory and voluntary) in service provision. We have all seen houses full of equipment that is collected to 'solve the problem'. But does it? More is not necessarily best. All equipment needs to be reviewed in relation to changes and other items that are issued and used, new items, the child's 24 hour day, the environments in which it is used and the changing needs regarding programmes, lifestyles etc. If equipment is issued in collaboration with the NHS perhaps the review of the items could be taken on by the statutory providers even if financial collaboration is not possible. Is this a way we can hold hands? We will also be re-cycling as much

equipment as is possible. If you find any of our equipment being stored in dark cupboards or not being used at home, could you contact us for collection of the items? We are also looking to 'recruit' a network of therapists who will act as primary assessors for the charity in their locality, linking with the Whizz-Kidz regional therapist to ensure duplication does not occur and that the correct children are targeted first. Of course there will be payment for your time. So if you are experienced in powered, manual or high performance models (or want to learn more about paediatric provision than you do already), please let us know if you are interested. The offer goes out to therapists and rehabilitation engineers, either sex!

The need and provision for the social mobility equipment such as tricycles, adapted bicycles and sports models will continue and the quality of life benefits we will endeavour to evaluate. If you would like to talk to us or find out more about how Whizz-Kidz could work with you, please call us and ask to speak to Cerie, Emma, Jannine or myself in the Children's service section. We look forward to hearing from you in the Millennium!

Ros Ham

Director of Clinical Services



#### **Notice Board**



Date	Venue	Title	Contact	
January 2000				
25	London	The Society for Research in	tel. 0115 9691169 ext. 47500	
		Rehabilitation Winter Meeting	Fax. 0115 9627992	
Manch 2000			email: Ann.Hughes@nottingham.ac.uk	
March 2000				
26 - 28	Dubai	Third International Exhibition	Fax: +971 4 378788	
		and Congress on Rehabilitation		
28-02July	Orlando, Florida	RESNA 2000 Annual Conference	tel: +1 703 524 6639	
			email: RESNAA2000@resna.org	
15	York	Wheelchair stability meeting	tel: 01522 577219 fax: 538752	
			email: roger.potter@ldhc.trent.nhs.uk	
April 2000				
10 - 12	Llandudno	National Conference of the PMG	tel. 01223 882105	
September 2000				
11/12 - 14	Southampton	6th Annual National IPEM Conference	tel. 01904 610 821	



#### Mitchells Marvel's

If one hours
sleep before
midnight is worth
two after, you
could get a full
nights sleep
between 6 and 10
and still be
around for last
orders!



#### LITERATURE REVIEWS

# Passenger Safety -WHEELCHAIR GUIDE. Ref: QB15/1244 (6/99)

Publ. UNWIN Safety Systems £10\* from C.N. Unwin Ltd. Willow House, Artillery Road, Lufton Trading Estate, Yeovil, Somerset. BA22 8RP.

#### \*First copy free to each organisation.

At a time when there is so much confusion regarding safety of wheelchairs on transport, this is a welcome publication which provides clear guidance regarding which systems should be used with which model of wheelchair.

As stated in the forward by Campbell McKee, Managing Director, Unwins have a wealth of experience and knowledge in the field of providing safety systems for wheelchair users and, to the benefit of all concerned, this is now being shared through this publication,.

The 57 page A4 size document starts by giving some brief information about Unwins and their involvement in crash testing. It then moves on to give a summary of essential points regarding the transporting of people in wheelchairs. It should be remembered that with the Access section of the Disability Discrimination Act gradually coming on line, that there are different standards for different modes of public transport and, apart from taxis, public transport will not have any means of securing wheelchairs, though may, in some cases, have a bar or division to separate wheelchair users from other travellers.

Wheelchair Restraints and Passenger restraints are next clearly described and illustrated with examples of how and when they can be appropriately used.

The remainder of the book is dedicated to use with individual chairs, supported by many illustrations, a description and chart which indicates the type of chair, weight and which safety systems are recommended for use. In all, some 400 products from 32 manufacturers are covered.

This is an excellent practical publication. It is important that the reader takes note of the statement on the inside of the cover and the comments in the Managing Director's forward which highlight several important points including the fact that training is essential and that safety systems are only effective if they are correctly fitted and used.

Copies of this document can be obtained from Unwins, Cheques should be made payable to Unwin Safety Systems at the above address. Further enquiries to be made to: Emma Connell. Tel/Fax: 01935 410920. E-Mail: sales@unwin-safety.co.uk

## THE MANUAL WHEELCHAIR TRAINING GUIDE.

Peter Axelson, Denise Chesney, Jean Minkel and Anita Perr Publ. PAX Press Santa Cruz. Price £16.99 plus p&p £1.25 available from: BES Rehab Ltd. 9 Cow Lane, Fulbourn, Cambridge CB1 5HB

With an additional author but otherwise from the same group and stable (Paralyzed Veterans of America) as A Guide to Wheelchair Selection this publication has similar appeal due its attractive cover and cartoon illustrations

There are 140 pages packed with practical information aimed at helping wheelchair users to get out and about by getting the best use from their wheelchair.

As stated in the advertising sheet, this is an easy-toread, comprehensive book on wheelchair mobility skills. It is also humourously but usefully illustrated (260 illustrations I am reliably informed) and covers everything from Set up for adjustable wheelchairs to negotiating a variety of surfaces, asking for help, (ask the jogger, not the man in the suit as he won't want to dirty his hands), safety on ramps and many, many other practical situations and challenges, too numerous to list. The final chapter moves on to night-time safety, hiking!, travelling and weather. There is no doubt that the Paralyzed Veterans of America are focussed on people with Spinal Injuries and even though some of the advice and procedures shown are only for the more active and able user, a great deal of this information is for all users - and their carers. There are many 'Americanisms' (not surprising as this is an American publication), but rather than causing an irritation, I found these added to the pleasure of the book. Crossing a 'Trolley track' may conjure up pictures of the elderly 'tea-set' for the English, but in this publication you

need to be able to 'pop a wheelie' if you are going to make the grade. I am not sure of the difference between an 'assistant' and a 'spotter' (not for the birds?) as both seem to help, though on a quick glance through the text, it seems that an assistant has to have more strength than a spotter who guides and supports in most instances.

Whilst only truly active users might well purchase and read this publication from cover to cover, I felt it was definitely of use to all assessors, prescribers, carers and anyone working with wheelchair users and involved in encouraging them to make the most of life and their wheelchair.

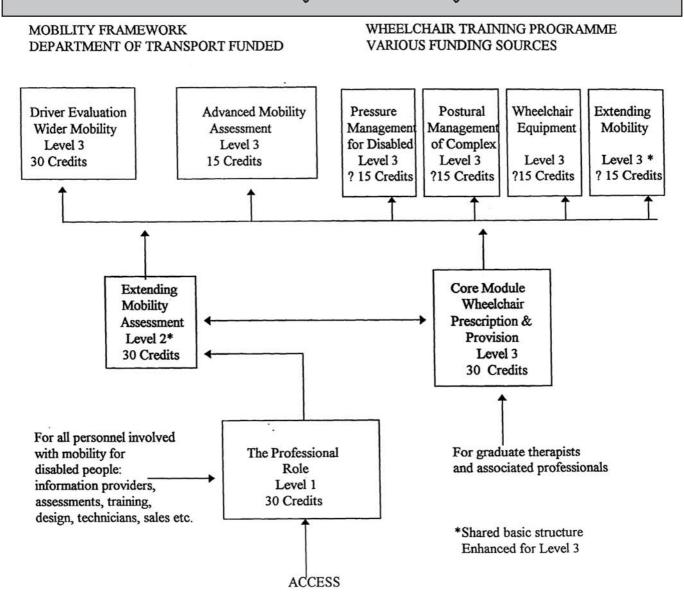
Certainly one for the department shelf, though it may extend the coffee break once you start dipping into it.

For people who had trouble tracking down the 'Guide to Wheelchair Selection' from the Paralyzed Veterans of America, this publication is readily available in the UK from BES Rehab. And if you enjoy this Guide, you will be pleased to know that The Powered Wheelchair Training Guide is due for publication later this year.

#### Patsy Aldersea

Occupational Therapist Merton and Sutton Wheelchair Service Manager

### Wheelchair prescription and provision core module Accredited at Level 3 by The University of Greenwich



The above framework illustrates the range of courses planned and the interaction between the different modules. For readers of the CIGOPW newsletter, the absence of a vital arrow failed to illustrate that the core module is essential for access to the other level 3 modules. This is to ensure that there is equality of standard and knowledge for all who successfully complete any or all of the modules. For more information contact **Patsy Aldersea**.

# The PMG LLANDUDNO MILLENNIUM CONFERENCE 10 ~ 12th April 2000

Working Together: 'The Whole is Greater than the Sum of the Parts'

This years conference looks to be the best yet. The theme 'working together' will challenge us to examine the barriers of working with different agencies and services in the field of posture and mobility. Why? So we can form a consensus opinion on how these problems can be overcome and make the most effective use of the resources available to improve the services we provide.

# £40 free book voucher

Monday the 10th kicks in with the keynote presentation by **Dafydd Wigley** (leader of Plaid Cymou and MP for Caernarfan) entitled 'working together' which will be followed by the much awaited Audit commission report on aids and equipment.

Over the course of the 3 days there will be 6 free papers, 3 clinical case studies and various technological presentations. The exhibition will be extensive, giving a chance to look at the latest equipment developments and chat

#### Up to £500 to be won

studies and various technological presentations. The exhibition will be Conference they might make a lot of hard work very worthwhile.

As if presenting a paper wasn't enough!

to the manufactures and suppliers of the products we use in a relaxed atmosphere, particularly Monday evening where there will be **free wine** on offer.

Andrew Bruce begins Tuesday's presentations talking about 'issues for working together for users' followed by an interactive session to identify barriers to integrated services. The points raised will be discussed during the workshops later that day. R&D funding will be addressed by Mark Lewis and Emma Parry will expand on her latest work at SCAMP. There is all to look forward to on Tuesday evening, with the conference dinner and disco.



Chance to relax at the conference dinner, with free wine and and shake a leg during the disco - but watch out for the paparazzi!

Wednesday offers presentations by Emlyn Williams on 'Environmental controls - Integrating Assistive Technology' and Sheelagh Richardson presenting the York

report and implications for wheelchair services. Feedback from Tuesday's workshops will formulate how the various issues discussed can be carried forward.

All in all this conference offers extremely good value, good education and training, good networking and above all, good fun.









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Internet: www.foam-karve.co.uk

#### Foam Karve is the fastest specialised seating in Great Britain, Press release 9th June 1999



Delichon limited, the Wheelchair Seating Specialist that developed Foam Karve, is celebrating making the seat used to break the British land speed record. A new record of 269mph was set at Elvington airfield, Nr York, in a specially built, jet powered dragster.

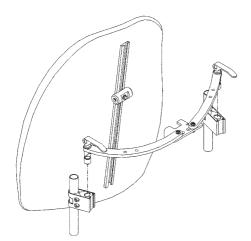
Marketing Director Forest Paget explains, 'since the longest runway in Britain is only 3 miles in length, it is necessary to accelerate and de-accelerate the car very quickly. The accelerations of up

to 12 G give the driver an effective weight of 1 and a quarter tones. A custom Foam Karve seat was chosen as it spreads the loading over the whole of the drivers back and ensures he is safely and securely held'.

Wheelchair seats, just like racing seats are produced on location 'while you wait'. A cast of the person's shape is taken using an evacuated bead bag. This is then copied into a foam block using a Foam Karve mobile machining centre. Composite foam technologies provide the users with a combination of posture control and pressure management.

For wheelchairs and racing cars the Foam Karve process takes just 60 minutes. This rapid production time, plus the land speed record success means that Foam Karve really can claim to be the fastest specialist seating company in Great Britain.

#### V-Trak is back on track with Delichon, Press release 1st October 1999



Delichon Limited, the wheelchair seating specialist that developed Foam Karve, is now solely responsible for supplying the V-Trak (formerly Vectrac) system and Therapod backrests. Manufactured by Performance Health Products Limited, V-Trak is the quick release adjustable interface for use between the wheelchair and backrest.

V-Trak is a trak attached to the back rest that has five (V) possible adjustments to vary back rotation, height, depth, centre and recline. Thus with optimum positioning the patient can experience the desired combination of comfort and correct posture. V-Trak utilises the uprights present on all wheelchairs, is quickly released for folding the chair and can interface to almost any type of seating system.



FOAM Marketing Director Forest Paget explains, 'the adjustments that are possible with V-FOAM Trak and the ability to interface to so many chairs are major factors that contribute to the very height success rate of our own Foam Karve seats. For this reason we have chosen to invest in improving and promoting V-Trak. We want to ensure that every- $K \land R \lor F$  one can enjoy the benefits today and that in the future the functionality of the system  $K \land R \lor$ will be further developed.'

