POSTURE &
MOBILITY
GROUP

# POSTURE & MOBILITY

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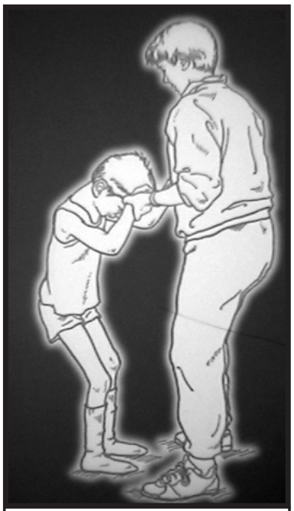

**Guess the Product**

# Mitchells Marvel's

Picture this; mother is shouting upstairs trying to wake young sibling for school. See if you can work out the translation from Yorkshire to English

YUP

MUP

YUP YIT

MUP NOO

Page 16 if you need help.

## Quick note:

Because of the delay in getting this issue out, you will be treated to a pre-Christmas edition. Any offers to report on the meetings listed on the notice board will be most welcome.

We are also looking for a wheelchair service/seating service/postural management service to do an article on how they operate, the ups and downs etc.. Please contact Phil Swann if you would like more information. See below for deadline details.

## Advertising costs:

Full Page: £ 300
Half Page: £ 150
Quarter page£ 100

Contact Phil Swann if you're interested

## Guess the Product:

The product featured on page 21 of volume 12 was a **Rea Assist chassis** - I was overwhelmed by the responses! Well done to anyone who guessed it correctly, sadly the prize remains unclaimed.

The next issue of Posture & Mobility will be in **Dec. 2001** The deadline for this issue is the **16th of Nov.** 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) email them to Phil Swann or post a floppy.

The Posture & Mobility 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

"We assess each user for their individual needs. We meet our clients clinical needs. We provide a flexible Needs led service"

**BUT** "We don't have a chair that meets your needs,our budget doesn't allow us to have one of those".

"We know you need it but sorry we can't provide it. We have run out of money for this year. There is a two year waiting list."

"Its not me personally you know it's POLICY, THE MANAGER, THE COMMISSIONERS, THE NHS"

How often do we hear that? How often do we say it? The user accepts it because they all know the state of the NHS!

But are we all too ready to say it's not our fault and then do nothing about it?

Is it not the responsibility of us, the clinical specialists to pass on loudly and clearly to those above us, the needs that are not being met and how the service can be improved?

Does the cardiac surgeon tell his patients, "we have run out of money?" Do his patients wait longer than 18 months for the most minor procedure? The answer to both is "No". He is the professional and he knows that if it is clinically needed, the money will be found and that no one in the UK waits for longer than 18 months for anything-except wheelchairs and seating - of course!

Health professionals must not forget what they have been trained for and are in clinics for-to assess for need, identify how to alleviate disability and increase function and well being, to make people independent so that they can function in the wider community and reduce their dependance upon others! Equipment is a key factor in this process and is **CHEAP!!**

Wheelchairs and seating are a fraction of health costs especially when you consider costs of surgery to correct deformity, pressure sores, and community care.

There is only a limited amount of money available in the NHS but unless we the 'ground force' put continuous active pressure on those in positions of influence, nothing will change because those in authority will not know what change is needed.

**Julia Cunningham**
*Whiz Kidz therapist*

# Letter from the Chairman

### Introduction & York Conference

What a great conference York turned out to be, at over 400 delegates the largest yet and rewarding all of us who organised it as well as those attending. It was particularly gratifying to inaugurate the Aldersea Lecture with a presentation from Patsy herself. My grateful thanks to B.E.S. Rehab, our conference organisers, ably led by Barend ter Haar, who coped brilliantly with a massive increase in registrations during the last two weeks before the conference. And thank you all who attended and supported the PMG by doing so. Your conference feedback forms have been analysed and the results, published in this edition, are being used to plan the next conference at Nottingham on 15th & 16th April 2002. Hopefully we will do even better there. Last but not least, a big thank you to the exhibitors who support our conferences with their attendance, latest products and expertise. In addition, the exhibition fees they pay enable us to keep the registration fees at an affordable level.

My report to the AGM at York is reproduced elsewhere in this edition so I will be brief here in summarising your committee's work so far this year.

### The Committee & CPD

Your new committee consists of 15 members, 5 of whom volunteered to be co-opted at the AGM after the proposal to increase the committee from 10 to 15 was agreed. Nominations will be invited at the next AGM to confirm or change the co-opted members plus any other vacancies which occur at that time. In the meantime I would like to express my gratitude to those who volunteered for their interest and support and congratulations to those who were nominated and elected at the AGM.

We will have had four meetings of the committee by the time you read this. Not all members are able to attend at each meeting, of course, but the benefits of more people, and all of us on e-mail, are beginning to evolve as actions and activities are delegated to individuals or small working groups in an effort to accomplish the many tasks we have set ourselves in already busy lives.

I heard that some members are unsure about whether standing for election to the committee might result in them incurring costs to attend meetings and I would like to clarify the situation:

Membership of the PMG committee is considered a professional activity attracting credits for CPD (continuing professional development) and as such it should be supported as relevant activity by employers. In some situations this requires discussion before being nominated. PMG cannot reimburse committee members for their time.

PMG will reimburse committee members for costs incurred in attending meetings or undertaking any other approved PMG business if members cannot retrieve these costs from elsewhere. The definitive policy on this is currently being clarified and will be available for those requiring it.

### Charitable Status and the Constitution

The membership almost unanimously supported the proposal to seek charitable status for PMG at the last AGM. I was particularly gratified by the confidence shown in the committee when you voted to accept the revised Constitution (required by the Charity Commissioners) mostly unread and largely on the recommendation of the Committee that it was essentially the same as our previous one in it's intent. Thank you for that. The revised constitution is published in this edition together with a note of our progress towards this objective.

**Scottish Seating & Wheelchair Group (SSWG)**

Discussions about closer working between SSWG and PMG have started and continue. Sharing of committee meeting minutes, representation on each committee, presentations of each group's activities at the other's conferences and the prospects for a joint meeting in the near future are the initial topics under discussion. SSWG have a good network of representation within the provider and funding bodies and links with other professional groups that PMG could learn from in an effort to avoid duplication and increase our voice. I look forward to increasing collaborative working between us.

**Website (www.posture-mobility.fsnet.co.uk) and Guidelines**

Our website and PMG Wheelchair Guidelines need updating and work is underway on both led by Dave Calder our co-opted member for these activities. If you have suggestions for inclusion on the website or in the guidelines we would be very pleased to receive them. Updating guidelines in this climate of rapid change is no mean feat without reverting to less than helpful generalisations. I do not envy Dave his task!

**Finally….**

….a reminder that the PMG is your group and the committee work on your behalf. We need your input to do this and welcome suggestions, comments and constructive criticism either directly to the secretary or via the letters section of this Newsletter.

Thank you.

Roy Nelham

**Roy Nelham**
*Chairman*

## 24 HOUR POSTURAL MANAGEMENT (PM) ~ WHERE TO FROM HERE?

### Objective

This session assumed the participants knew about and supported the principles of 24 hour postural management (24hr PM). The objective was to explore various aspects of this approach with a view to discussing and designing a service which the participants considered effective.

### Summary

An agreed definition of 24hr PM was reached and the evidence of the effectiveness of this approach discussed.

24hr PM is the management of someone's posture in the positions of lying, sitting, standing, walking and using mobility devices such as wheelchairs and tricycles. It includes the use of therapy and appropriate equipment to facilitate practical skills, achieve a developmentally appropriate posture and to help prevent deformity, together with periods out of equipment.

Evidence includes publications on position as a cause of deformity, anecdotal and clinical evidence of change from individual experience, a retrospective study of the impact on hip migration of different postural management applications and surgical approaches (Pountney et.al.) and a current prospective study of the effect of 24hr PM on hip migration and spinal curvature (Pountney, Chailey Heritage, work in progress). Calculating how long disabled children are in the care of their families and how many hours they are in bed emphasises the need for more than just seating and the importance of the family in implementing this approach, see Just "doing the sums" below in Training of Families. Collection of further evidence through the wider application of 24hr PM is required.

In considering outcomes, the question "whose outcome is it?" needs to be addressed before deciding on the appropriate measure. Several outcome measures including orthopaedic, were explored but further work is required to refine the process.

The training needs of professionals and families was related to the training available. Only three courses focused on 24hr PM were identified. Training with an emphasis on client agreement to positioning and client choice is required in provision of a service that has such an impact on family life.

Providers of existing services for various aspects of 24hr PM could communicate and collaborate more to facilitate more effective service delivery and development. A case manager approach to act as co-ordinator of services and client advocate was favoured.

Re-naming wheelchair services to 'Posture and Mobility Services' was seen as away to create a base for future co-ordination of services and the Case Manager. Emerging Primary Care Trusts were considered an ideal forum for development of local 24hr PM services using multi - and cross-agency working but only if the speciality of this service is recognised.

24hr PM was defined as follows:

a) 24hr PM is required by someone with a motor impairment resulting in impaired postural ability.

b) 24hr PM is the management of someone's posture in the positions of lying, sitting, standing, walking and using mobility devices such as wheelchairs and tricycles. It includes the use of therapy and appropriate equipment to facilitate practical skills, achieve a developmentally appropriate posture and to help prevent deformity together with periods out of equipment.

In addition, it was agreed that the equipment used for 24hr PM should facilitate:-

c) a higher level of physical ability than is possible when not using the equipment,

d) consistent and repeated sensory input for all postures,

e) a correct starting position for movement,

f) movement within limited boundaries within which the person is able to recover their posture,

g) security and stability to facilitate practical activities.

Frequent changes of position throughout a 24 hr period are required to facilitate stretching and relaxation of different muscle groups.

## Evidence of Effectiveness

Roy Nelham led this discussion. There is much clinical, anecdotal evidence of the effectiveness of 24hr PM. There is also a validated and reliable theoretical basis founded on normal development and the associated developmental biomechanics. In addition to the well established publications on position as a cause of deformity there is some retrospective research which established the benefits of using 24hr PM to reduce hip migration and dislocation. Further research under way and more is required to influence practice and funding. It is important that a framework and guidelines for the provision of 24hr PM services are in place to facilitate wider availability and enable methodical collection of the evidence for the ultimate benefit of the clients.

## Training of Professionals

Sandy Clarke and Jo Jex from Active Design led this discussion and highlighted the four key stages that professionals are currently involved in namely;-

- referral,
- assessment,
- prescription and planning and
- implementation of the prescription.

Just about every one of the wide range of professionals working with or providing services to a disabled child could be involved in 24hr PM. A major challenge is how to meet the varied needs of all of these professionals.

A wide range of general training in posture and mobility is currently available. Those focusing on the 24hr PM approach were identified as the Chailey Approach (provided by Active Design), the Symmetrikit/Helping Hand training and the Mary Marlborough Centre course. CORE also included this as a small part of its rehabilitation engineering training. Bobath training covered the whole child but has little emphasis on the use of equipment or 24hr PM provision. Clearly more needs to be done but improved access to, and better use of the training that currently exists would be of a benefit and may be more easily facilitated in the short term.

Training and collaboration of local service providers is needed in order to achieve a consistency of approach and understanding across the services in the delivery of 24hr PM.

Training in various assessment tools was identified including the Chailey Levels of Ability, the Goldsmith Index as well as the importance of various photographic and or video techniques, clearly documented client notes, appropriate history taking and examination of the client and measurement of x-rays. An emphasis was placed on collecting client information 'through what you see and what you feel' i.e. skilled observation and hands on assessment, another training need for some.

There was an urgent need for a standardised language for common understanding, communication and collection of evidence (International Standards Organisation work will contribute to this). Training in communication was needed especially in listening skills and especially with families to assist in their understanding of what was happening to their child, what the child's physical needs were and in giving "bad news" as well as to facilitate the professionals' understanding of the families' needs.

Another training need was for service providers to be able to cope with, and communicate without guilt, negative aspects such as lack of funding, 24hr PM currently being beyond the abilities of local services, etc. It would be important to document clearly all such aspects if service development is to be promoted. Also, some training in how to do nothing and live with that if that is what the client ultimately prefers.

Evidence of effectiveness and the Continuing Professional Development needs of professionals can help stimulate training and promote its funding. There are also potential financial gains by reducing progression of deformity and thereby reducing the need for increasing services including surgery. While all services have waiting lists it is unlikely that financial arguments will result in the transfer of funds but the evidence should stimulate new funding under Clinical Governance.

### Training of Families

Liz Goldsmith presented the breakdown of hours spent by a school aged disabled child throughout a year under a heading of "Doing the Sums" ;-

**8,760** hours per annum

**1,440** hours at school including journey time

**7,320** hours in the family of which **3,600** hours is in bed.

The key to the success of any 24hr PM programme are the families. It is they who manage it when the professionals are not available. We need to recognise that habitually bad positions at home can be compensated by good positioning for as much time as possible. Outcome measures have to recognise family life. The families teach us about their child and we are seeking collaboration (not compliance) i.e. a desire to change underpinned by the knowledge of why.

Helping Hand have produced an illustrated Postural Profile, which belongs to the child and family, to describe clearly the postural needs of the child, how these are being met and when, how and from whom to seek help. Regular telephone contact, workshops and follow-up support is part of the overall package of training and supporting families. Workshops are fun with a mixture of information giving, partying and hospitality.

The family being involved in a hands on way with the child's assessment and prescription processes helps with understanding and ownership of what is happening. It is important the family stop measuring changes if the child is deteriorating as this can reinforce a sense of failure. The emphasis has to be placed elsewhere in the child's care for some positive objectives and outcomes. It is important not to expose families to the opportunities and possibilities of a 24hr PM approach if this is unavailable to them in their area.

Liz reminded us that families (and many professionals ..... ed!) need to know that their child will go through rough patches in terms of losing postural skills and ability as well as practical skills. These rough patches will include growth, illness, family crises and other influences significant to the child. This emphasises the importance of trust in the relationship between the professional and the family so that the family can share confidential information, such as family crises, that might be relevant to the child's change in abilities.

There was general support for the appointment of postural care workers who could be equivalent to therapy aids to assist the professionals, be the educators and advocates of the families and the liaison between or co-ordinators of service providers. They would provide monitoring and support and identify the need for re-referral back to services.

It is important to acknowledge and document a family's lack of interest or ability or their neglect of their child's special needs or their decision not to collaborate etc., as this will clearly impact on the success of this approach. Also, as evidence increases of how 24hr PM can prevent deformity there may be increasing risks of the parents suing because of failure to prevent their child being deformed. It is important that the professionals have adequate evidence of their efforts and objective comments on how or why they were rejected or unsuccessful. Liz warned us all to "watch your back".

### Outcomes

Elizabeth Green asked the questions:

Whose outcome is it?

What is its measure?

She then listed a range of possible outcome measurements including the Goldsmith index, X-rays, Chailey Levels of Ability, Gross Motor Function Measures, Gross Motor Qualitative Measures, Test of Playfulness, the need for surgery, etc. It is important to document practice and objectives etc., in a measurable way in order to have appropriate outcome measures, some of which are simple such as:

- photography
- comfort score on a scale of 1 - 10
- “handle-ability” of client on a scale of 1 to 10
- outcome measures based on what clients want out of the process rather than someone else’s outcome.

This requires client generated indices which may be complicated as clients often can’t say what they want out of the process.

There may be a need for different outcome measures to support and confirm clinical activity and to justify funding, the latter requiring an outcome which is understandable by finance directors etc. Many quality of life measures eg SF 36 etc. may not be standardised for children and more investigation of these is required.

There needs to be introduced into the clinical processes a formal client acceptance procedure which implies consent to treatment. This would include a statement of prognosis with and without the planned intervention. What do we do in the situation where a child’s views are different from those of his/her parents?

Services need to have a flexible responsive review process which takes into account unpredictable client changes.

It is important to set up an environment where it is acceptable not to use equipment and to say so and document it with the reasons why, e.g family crises. Outcome measures will also be dependant on the input of therapists and others who are part of the team monitoring and supporting the use of 24hr PM. This process is impacted by staff retention problems, relationship development and trust between staff and families which is impaired if staff change. All of these factors have an affect upon the use of equipment and thereby its outcome. It is important to document changes in order that outcomes can be correctly attributed to all the factors which could otherwise be hidden within the process.

## Provider Prospective

Jacqui Donaldson described how her service in Macclesfield buys in professionals and services to work towards providing 24hr PM, whilst only having service responsibilities for wheelchairs and special seating.

The question of who provides what was raised consistently throughout the session and the following were suggestions for potential collaborative service providers;-

- wheelchair services (for wheelchairs and associated seating)
- paediatric therapists in child development centres, in education and in charities (aspects of posture and mobility)
- community therapy services (aspects of posture and mobility)
- parents (aspects of posture and mobility)

She described how therapists have to work very hard to co-ordinate and introduce the various aspects of 24hr PM such as;-

- identifying and establishing the various complementary providers and suppliers,
- the actual provision processes,
- seeking and establishing funding,
- identifying responsibilities and boundaries,
- co-ordinating those with the responsibilities,
- bridging financial and employment boundaries.

The following is a summary of what works in Macclesfield:

- small is beautiful - close to the clients and professionals - knowledge of each other
- liaison and communication - all those involved have to be accessible to each other
- sharing of knowledge between key people
- feedback loop - therapists in the field are relied upon to refer back

Potential barriers to the provision of 24hr PM were listed as;

- Lack of education and training
    - for static seating
    - for those in the field
    - for those referring to services
    - for those for whom it is not their responsibility
- Lack of identified responsibility
- Limited evidence base
- Client not wanting to collaborate

- Tissue viability - tissue trauma management may not be compatible with postural control
- Lack of resources
- Lack of co-ordination of existing professionals and existing resources
- Lack of co-ordination of specialist services

## Client Perspective

For various reasons it was not possible to get a client or a client's family to this session. Delegates were asked to present what they knew from their own personal experience of what clients say.

The preference seemed to be for a one stop shop although others would say they were prepared to go anywhere provided they could get what was required. Clients also wanted one assessment procedure rather than have to go through several assessment procedures repeating the same or similar information with a series of professionals.

Clients and families want information on what can happen to their child, how to prevent that and who does or can do what (contact information). All of this should be available from diagnosis and repeated and added to as appropriate at each relevant stage of the child's development or significant clinical activity thereafter. The information needs to be in writing in a format and language that is appropriate for understanding, referring to and acting on. The clients and their families also want easy access to services with no "arbitrary" geographical or organisational barriers that attempt to divide their child and his/her needs into parts. They also want rapid responses to initial referrals and, once needs have been identified, rapid response to provision to meet those needs. They live with the problem every day and want a total approach to look at all issues to include lying, sitting, standing, hoisting, toilet use, bathing, travel, i.e. the normal activities of family life. Meeting special needs should not get in the way of ordinary needs.

## General discussion

Discussion ranged over many aspects of 24hr PM and how it may be organised, co-ordinated and delivered as well as reviewed, monitored and outcomes recorded. There was no dissenting view about the importance of 24hr PM. There was general support for a case manager approach for each of the clients to assist with the co-ordination of what are currently fragmented services. The case manager would be able to bridge the communication gap between existing services and bring together professionals and services who currently are not working together. The case manager may need to be a therapist or at least a therapy helper in order to understand the issues and speak to professionals and service providers in a meaningful way and could serve as the eyes and ears of professionals as well as being an advocate for the clients. They need to have sufficient training, knowledge and understanding to be able to decide which service to refer to and how to co-ordinate those that exist. Many parents currently battle to fill this role for their children which can create extra stresses within a family but some parents may wish to be the case manager for their child with appropriate training and support from professionals to empower them to do this.

Having up to 15 professionals in a room for a multidisciplinary all encompassing clinic can be highly intimidating for the client and may not be successful in obtaining the client's view. The professionals could delegate assessment and prescription processes to a smaller team, who are appropriately trained and in whom they have confidence, working with the case manager.

There is a need to work in an interdisciplinary as well as multidisciplinary way in order to work in a seamless way with the client and families and this requires some training. Other professionals with whom the client interacts including consultants, school therapists, educationalists and social services professionals need to be included in this. A model similar to that for the tissue viability nurse was proposed - an example of an informed specialist co-ordinating other professionals to provide for their clients. The case manager working across agencies at a local level and with the expertise required would help to prevent clients falling through gaps in existing services.

There is a need for specialist expertise nationally to be cascaded down to district level and then down to the range of other local services at client level and family level. This would require a national perspective which the PMG may be able to address.

The need for joint working, at a local level, between all the agencies involved in the various environments in which clients find themselves is fundamental. It was agreed that 24hr PM is a healthcare need requiring healthcare funding as it addresses the client's impairment, their disability and the risks of developing deformity with consequent higher and ongoing healthcare needs. Shared funding for a health led role would be an alternative.

The education statement of need is a powerful tool for disabled children. There should also be a statement of postural and mobility need, which is equally powerful. This should be a ‘stand-alone’ document in order to be valid for adults as well as children. The Postural and Mobility Statement of Need would set a framework in which posture and mobility needs could be identified. It would establish the right of each child to such an assessment and the statement would bring with it an obligation to provide. Funding would need to be provided centrally to support that. It is considered that posture and mobility are equally essential to a child’s development as education and should have the same status of provision. Establishment of services for children must then drive equivalent services for adults if the investment is to be capitalised on and not wasted.

## Implementation and Planning

Throughout this session importance was placed on the client’s choice, consent and their understanding of the social dimension of the use of 24hr PM, and the impact this has on the whole family. The importance of clearly identifying and documenting the client’s needs together with agreed objectives and outcome measures was stated. These are important and focal aspects of service delivery and can sometimes be a salutary exercise for the professionals.

A Statement of Physical Need is required to run alongside or be integrated with the Statement of Special Needs for Education in order that the status of postural and mobility needs for disabled children was given the same profile as educational needs with the attendant rights and obligations for assessment and provision.

The need for communication and joint working at different levels including commissioners and managers of a range of services was identified as a major component in the planning and delivery of 24hr PM services. The role of a case manager for each client was considered to be beneficial to this process.

There was a general consensus that the existing wheelchair services with their responsibility for mobility and seating could be the core of further development and be expanded into and renamed Posture and Mobility Services. This service would provide and co-ordinate local provision through advocates or case managers who would make a case for continuity of care to children and adults regardless of post code. Training and education will be required to get the new Posture and Mobility Services off the ground. This has been done once successfully for the wheelchair services after devolution and could be done again.

There was also a discussion about the need for collaboration between many different, and now changing, services in order to provide lying supports and standing supports, the responsibility for which is not clear in many areas. The NHS Plan for client involvement in their service provision and for collaborative working should be helpful in this process.

It was noted that the new primary care trusts are willing to carry such ideas forward for their local populations and are looking at provider forums to cross all agencies. This could be a very powerful way forward for local Posture and Mobility Services and may be a source of appropriate funding, staffing, support and philosophy to achieve these objectives.

The session ended on this high positive point.

**Roy Nelham**
*Chairman*

**Move 3 coins in figure 1 to make it into figure 2.**

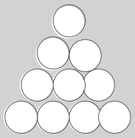

Fig 1

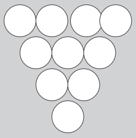

Fig 2

# PMG Annual Conference: York 2001

## Winner of Free Paper Competition

## THE IMPACT OF WHEELCHAIR DESIGN ON THE SELF-IDENTITY OF USERS AGED 16-19

Advances in technology and wheelchair design have resulted in applications to charities for funding. Public accountability requires demonstration of effectiveness. Young physically disabled people can be psychologically impaired by lack of appropriate equipment. anecdotally positive change in self-identity is considered an outcome of provision, but there is little supporting evidence. Research has shown a correlation between self-identity, personal adjustment, well-being and mental health. During adolescence, self is defined and identity formed, establishing a worldly location, necessary for adult life.

This study used qualitative, in-depth, semi-structured interviews to generate an understanding of the individual's experiences of the impact of wheelchair design on self identity. Subjects were 3 males, 3 females, age 16-19, full time wheelchair users with congenital conditions. All had long term wheelchair experience but were provided with specialised wheelchairs in the last 6-24 months. Taped interviews, having familial privacy, provided raw data for analysis.

Results showed self identity as an evolving process and this formed the basis for the categories: wheelchair design, self as agent, presentation of self, self-evaluation and self-concept. Ease of movement afforded by the wheelchair allowed the self to interact and influence; the environment as agent, supporting integration into society. Cosmetics and accessories influenced presentation of the social self, resulting in shifts of embodied power, while providing commonality between an able-bodied society and the disabled, as features acted as 'disidentifers' and symbols of prestige, promoting inclusion. The individuals through reflective narrative and self-evaluation reviewed their self-concept, as active creators. Movement and status were incorporated into self-concept, with design supporting an identity as a gender specific, young person. There was greater congruence of real perceived and ideal selves, improving well being and mental health.

Services should enable disabled young people to establish a positive self identity as proposed in the department of health's framework for assessment for children in need. With individual services having limited resources there is a need for statutory services to work together with charities and parents and to establish protocols for partnership funding, by extending the voucher scheme to powered wheelchairs.

**Anne Harris**

*Mobility Therapist, Whizz·Kidz*

## Winner of Poster Competition

## SINGLE SWITCH CONTROLS FOR TILT-IN-SPACE CHAIRS

People who cannot operate the normal handset controls for a tilt-in-space chair often become reliant on their carers for adjusting their posture. It maybe possible to include this as part of an environmental control system but often this is not technically achievable.

A case study is described which embodies the custom design of a wheelchair tilt-in-space control, using a single cheek switch. The control time limits the amount of travel for a given selection and provides protection against inadvertent switch operation. Use of the handset is unaffected.

This method has a wider application to other equipment such as such as riser/recliner chairs and could also provide a low cost means of minimising the risks of entrapment within tilting mechanisms.

**M. Wozencroft**

*Clinical Electronic Engineer, Mary Marlborough Centre*

**R Houghton**

*Development Engineer, Mary Marlborough Centre*

# Plenary Paper Abstracts

## Setting The Scene Objectives Expectations Reality And Impossibilities

Dr Elizabeth Green, Consultant in Paediatric Rehabilitation
Chailey Heritage Clinical Services

Postural management is the control of posture over the whole 24 hours - positioning in static postures of lying, sitting, standing; hands on therapy; active exercise. Postural management is needed if a person has the inability to maintain a symmetrical position in lying, sitting and standing; cannot change position independently or is at risk of developing deformity.

**Objectives:** To enable function, to prevent or reduce deformity and to improve the basic level of a person's ability by preventing unwanted movements

The evidence base for postural management is growing. Dynamic systems theory offers a theoretical basis. Increasing knowledge of muscle and bone plasticity and neuroplasticity suggests that changes in bone, muscle and tissue are possible at any age in response to external factors. It is recognised now that people with cerebral palsy require long repetitive sensory inputs to establish a motor memory. Retrospective research study findings demonstrate the efficacy of positioning in lying, sitting and standing.

**Expectations:** These vary according to the perceptions of the person involved. The feelings and knowledge base of the clinician, the patient, the parent or carer are different. Expectations are not always explicit and may not be based at all on reality! Examples include freedom from pain, independence, better appearance, improved cognitive ability, reduced need for corrective surgery, total availability

**Reality:** Lack of resources are a major problem. In general services are not organised to enable 24-hour postural management. Wheelchair services have been set up historically to provide wheelchairs and seating so that provision of other postural equipment is not planned for. Access tends to be unequal and very dependent on local provision. Disability services have to compete for resources in open but not equal competition with acute services addressing NHS Plan priorities. Postural equipment tends to be mostly unattractive, heavy and expensive. Patient choice cannot be always informed when a difficult and complex area is involved.

**Impossibilities:** A fast change of attitude and resources is unlikely in the current NHS climate. However it is equally impossible for services to remain unchanged in light of increasing evidence and clinical governance recommendations.

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## Measurement And Assessment Clinical Impact Of International Developments

R Nelham, Chailey Heritage Clinical Services
B ter Haar, B.E. S. Rehab

Working parties have been beavering away around the world over the last couple of years to try to produce consistent ways of measuring people and the items that affect their posture and mobility.

These groups have been working through the slow and steady process of putting together sets of standards. However, at the same time, they are each professional therapists, engineers, etc, so they are all keen that the standards will be useful to their professional lives.

The use of standards can be seen in every-day life - such as fuel consumption of cars. No-one drives, for example at 56 mph, but this figure is a useful comparator for giving a guideline as to how fuel hungry a vehicle is likely to be. Likewise in seating standards, the physical measurements from the tissue integrity management standard will not tell you which cushion to prescribe, but you will have comparative values available.

Paint colours are determined by standards, which mean that one batch can be compared with another, and we can be guaranteed that one tin will not give a different colour on the wall from the previous one. Likewise, the reference axis standard gives the clinician the chance to ensure that deformities, such as pelvic obliquity, are described in the same way around the world, and that seats can be made to fit the measurements provided. Ultimately this will also mean that the measurement process could be automated, and the data fed into computer-aided design of the seat.

# Transition To Adulthood

## Issues For Young People With Complex Needs

S Briggs, Principal
Beaumont College

Children growing up in Western Europe to day are able to follow a greater variety of opportunities in their transition to adulthood. The process for many young people is longer and increasing numbers of young adults remain in some form of dependency to their families until their mid twenties. Equally for young people with complex needs, in terms of learning, mobility, communication and sensory impairment, there is a greater variety of opportunities (and constraints), which mirror changes in legislation and provision.

Beaumont College provides services for young people aged between eighteen and twenty-five, acting as a key transitional service to support decision making and the exercise of choice in establishing a pattern of adult living.

The College uses multi-element support planning to create a personal prosthetic environment for each student, in order to ensure that young people and their families can more effectively negotiate with social services, health services and other agencies in obtaining the support needed for the young adult to achieve their personal goals.

The experiences of students and families are used to present a qualitative view of the provision of essential and less supportive aspects of the current ‘system’.

The conclusions drawn from a follow up study of students (with severe postural and mobility issues) who moved on from the College during the last three years suggest that a number of key considerations shaped the form of the ‘next step’ from the College:

**1) Family Efficiency**

The closest matches between the potential identified whilst studying at Beaumont College and the ‘next step’ were created by families who were able to contribute financially and/or mobilise additional or alternative support.

**2) Geographical Location**

Young adults with complex needs require complex, often scarce services. There is a wide geographical disparity between various parts of the country.

**3) Choreography**

In-a number of cases, the factor which promoted ‘best fit’ between expectation and the provision was the presence of a lead person or service which accepted responsibility to choreograph essential services.

The influence of the Disability Discrimination Act and the increasing trend towards inclusive education/community participation will bring greater opportunities and challenges. Transition from childhood to adulthood remains however an intensely personal experience and possibility of greater choice needs to be matched by equally sophisticated systems of support which allow young people with complex needs to create their own futures.

### Dilbert’s Rules of Order - Part one.

**Ever had one of those days...?**

1 I can only please one person per day. Today is not your day. Tomorrow is not looking good either.
2 I love deadlines. I especially like the whooshing sound they make as they go flying by.
3 Tell me what you need and I’ll tell you how to get along without it.
4 Accept that some days you are the pigeon and some days the statue.
5 I don’t have an attitude problem; you have a perception problem.
6 Last night I lay in bed looking up at the stars in the sky, and I thought to myself-where the heck is the ceiling?
7 My reality check bounced.
8 On the keyboard of life, always keep one finger on the escape key.

# The Hub And Spoke Model For Health Care Services - A Commentary

Robin Luff FRCS FRCP
Consultant in Rehabilitation Medicine

Dr Datta recently gave a presentation on the hub and spoke model for health care services to a meeting reviewing the recent Audit Commission report “Fully Equipped”. He mentioned wheelchair and seating services during his presentation and it seemed worthwhile exploring the subject further with regard to this specialist area within rehabilitation. Dr Datta has very kindly provided me with the text of his PowerPoint slides, which I have expanded into this short paper. I hope to stimulate discussion and perhaps debate during the York PMG Conference.

Dr Datta addressed his comments to three areas of health care provision: prosthetics, orthotics, wheelchairs and special seating. He compared the sizes of the populations treated against expenditure. He described the mechanistic form of service in which equipment was simply dispensed to prescription and outlined the weaknesses of this approach. The alternative style was characterised as an organisation providing equipment aiming to enable, rehabilitate, minimise complications and improve quality of life. He suggested that the most effective organisational style might incorporate both approaches.

If this combined approach were followed, were there any outstanding weaknesses, failures and problems? Dr Datta then reviewed the literature in the form of the various reports covering the clinical fields of interest from the Bainbridge Report of 1979 through to “Fully Equipped” which was published last year’. He was able to show that the present organisation of these three services had many deficits characterised by lack of cohesion, lack of integration, inequalities of distribution and therefore of access. He considered alternative models, discussing at length the hub and spoke concept, which has found favour in a number of recent reports.

The hub was described as a regional or sub-regional resource having dedicated clinical and management leadership. Its specialist services would be provided by professional, highly skilled multidisciplinary teams employing up to date clinical facilities and have access to research facilities and infrastructures. Prime responsibilities would be development of service strategies, ensuring clinical governance and lead in education and training.

The spokes “attached” to the hub comprised any other local site or organisation providing these services to the population served. Such sites would include neighbouring districts, district general hospitals, primary care groups, primary care trusts, schools, day centres and the homes of patients. Such sites would clearly not have access to the full range of resources identified for the hub and would benefit from access to the hub for information, expert opinion and specialist technical services.

Dr Datta then considered the benefits of the hub and spoke model. There would be economies of scale and best use of resources including management and other human resources. This would lead to clearer service strategy and cohesive overall objectives. Service provision would thus become more uniform and equitable. This would enhance the opportunities for continuing professional development, education and peer support and thus stimulate academic development. From this should come much greater opportunities for research involvement. Overall, the case for the hub and spoke model for health care provision, not new in itself is very strong and should be actively implemented in orthotic, prosthetic, wheelchair and seating services.

## COMMENTARY

I emphasise that these comments are my own and do not represent statements of policy; I make them to stimulate discussion and debate. Dr Datta makes a strong case for the model he favours which seems very much to emphasise the role of the specialist hub surrounded by sites providing basic level services to local populations. This seems to me to miss the point. Health care in the UK is provided through the general practitioner who must therefore be seen as the hub. Referrals are made for specialist advice and services on a consultation basis. Expert services are thus the spokes rather than the hub. I know of one wheelchair service local to my own which functions in exactly this manner; when specialist advice is needed, this service uses its own set of spokes to provide the necessary input. I am sure there are other perspectives on hub and spoke model and I look forward to hearing them either at the Conference or through the pages of the PMG Bulletin.

## A Review Of Equipment Provision For Postural Management

Lis Hook, Superintendent
Physiotherapist
King's College Hospital NHS Trust
Wheelchair Service

King's College Hospital NHS Trust Wheelchair Service, covering the inner London boroughs of Lambeth, Southwark and Lewisham, is frequently requested to provide seating systems on wheelchairs and buggies. This is to enable stabilisation of posture and maintenance of function as part of postural management programmes. However, two issues have been causing increased concern :-

**1)** Inequalities in provision of positioning equipment from other statutory services across the three boroughs:

**2)** The same statutory services requesting the Wheelchair Service to provide seating systems thus allowing them to avoid supplying positioning equipment themselves.

We set out to evaluate the supply of positioning equipment to children aged 2 -16 years living in Lambeth, Lewisham and Southwark:

- To establish levels of provision and gain evidence of inequality of supply across the three boroughs.
- A postal questionnaire was sent out to parents of children who have been issued with a seating system by the Wheelchair Service requesting details of equipment provision at home and school.
- Results identify that children in one borough benefit from a higher level of equipment provision compared to those living in the other two boroughs
- It would appear that " Postcode Prescription " is evident in the supply of positioning equipment.

We have demonstrated that there are inequalities in access to, and use of postural management equipment in Lambeth, Lewisham and Southwark. Pountney and Mandy (99) stated " There is a desperate need for an integrated approach to the provision of postural management services by multidisciplinary teams which have the expertise and funding to provide them. This type of service would improve dramatically the equity of service ". We are hopeful that in the future we can address the issue through joint funding via the primary care trust and social services.

**Reference:**

Poutney T and Mandy A (1999) *Postural Management and Clinical Effectiveness.* A.P.CP Journal 18-23

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## Quantitative Postural Assessment Using A Biomechanical Model

K. Lees, Rehabilitation Engineer
J.A. Cozens, Consultant in
Rehabilitation Medicine

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6LS

There is a need for objective assessment of posture in children and adults who require specialised seating. A digitising arm has been proposed as a means of measuring the locations of anatomical landmarks on sitting subjects (Maltais, Dansereau, Aissaoui and Lacoste,1999).

We are developing a vector based biomechanical model that defines relationships of digitised landmarks in terms of simplified body segments. The model includes landmarks digitised during plinth examination, which are not directly accessible in the sitting subject, such as the ischial tuberosities. The modelled relationships can be visualised as a computer-generated "stick figure". Quantitative postural indices can be calculated from the relationships between body segments, such as transverse rotation of the pelvis relative to the upper trunk.

We are piloting the use of the model with the digitising arm to provide objective assessment of posture in our special seating service. We are also exploring its use to understand the relationships between patients' sitting postures and any structural limitations found during plinth examination. The model and representative stick figures will be demonstrated.

**Reference:**

Malta's C., Dansereau J., Aissaoui R. and Lacoste M. (1999) *Assessment of geometric and mechanical parameters in wheelchair seating: a variability study.* IEEE Trans. Rehab. Eng. 7:91- 98

# Development Of A Method Of Measuring Force Through A Kneeblock For Children With Cerebral Palsy

R.L. McDonald, Pam's Research Training Fellow (Occupational Therapy)

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Child, The Wolfson Centre,
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London WClN 2AP

**Introduction:**

Many of the adaptive seating systems used in the United Kingdom with children with cerebral palsy use a sacral pad and kneeblock system to control the pelvis. The objective is to create a 'moment (turning effect) by the sacral pad to push the pelvis into a neutral position, which is then balanced and maintained by an opposing counterforce at the kneeblock (Green & Nelham, 1991 ). At present, published information about the efficacy of this type of system is of a descriptive nature (Reid & Rigby,1996).

**Research Question**:

Are the forces applied through a kneeblock and the resultant pressure measured at a sacral pad proportional to each other?

**Method:**

A force transduction device was developed, consisting of strain gauges attached to the normal kneeblock and developed in conjunction with Kings College Hospital Medical Engineering and Physics Department (London UK). Pressure at the sacral pad was measured using a commercially available skin interface pressure device.

Initially four children with cerebral palsy were seen on twice, over two days. Seven normal children also took part in the pilot project. They ranged in age from 4 to 12 years, and spent a morning or afternoon session using the special seating system.

**Results and Future plans:**

The initial data collection with children with cerebral palsy showed no identifiable relationship or consistency between the amount of pressure measured at the sacral pad and force applied through the kneeblocks. It was decided to pilot the sacral pad and kneeblock measurement system with children who did not have postural difficulties to establish a model of the relationship between force at the kneeblocks and pressure at the sacrum.

Mean force and mean pressure were collected and analysed together in the normal children and consistent relationship was found. Regression analysis was performed and a positive correlation of 0.777 between Force and Pressure was shown. The relationship can be expressed as:

**Mean Force (N) = -15 + 0.01 Pressure (Pa)**

The next stage of the project is to explore this relationship further with children with cerebral palsy, and assess this relationship over time. The results may then have implications for individuals using the system, and together with the other measures used in the project, may influence clinical practice for seating clinicians.

**References:**

Green E M & Nelham R L (1991), *Development of sitting ability, assessment of children with a motor handicap and prescription of appropriate seating systems*. Prosthetics and Orthotics International,15, 20316.

Reid D & Rigby P (1996), *Development of improved anterior pelvic stabilization devices for children with cerebral palsy.* Physical and Occupational Therapy in Paediatrics 16 (3), 91-96.

# IS POSITIONING IN EARLY LIFE ASSOCIATED WITH POSTURAL DEFORMITY?

[1]D. Porter, Clinical Scientist
[2]S. Michael, Clinical Scientist
[3]C.A. Kirkwood, Clinical Scientist

[1]Mary Marlborough Centre, Nuffield Orthopaedic Centre, Oxford OX3 7LD
[2]WestMarc, Southern General Hospital, Glasgow G514TF
[3]TORT Centre, Ninewells Hospital and Medical School, Dundee DD19SY

Fulford and Brown (1976) suggested that deformity in children with cerebral palsy may not be directly due to the neurological deficit itself but secondary to immobility i.e. a consequence of the effects of growth and gravity on a child who cannot voluntarily change position. It was thought that the position in which the child is nursed during the first year of life is particularly significant.  This view has been echoed in numerous discussion papers since has been generally accepted by many healthcare professionals. There is, however, little in the way of scientific evidence to support or contradict this hypothesis.

A database of postural information on non-ambulant people with cerebral palsy, seen at three centres in the UK, is being generated in order to study patterns of postural deformity. This research project is described separately on a poster at this conference. As a part of this project, parents of subjects under 19 years of age are being interviewed to identify preferred postures and positioning during the early life of their child. The interview concentrates on positioning related lying, holding and breast / bottle-feeding.

The objective of this study is to test a range of predefined associations between positioning in early life and the individual components of postural deformity such as the direction of scoliosis or windsweeping, which present later in life. The results from this study will be used to generate hypotheses for a more focussed etiological investigation in the second part of the research project.'

At the time of writing the abstract 132 parental interview questionnaires have been completed. It is intended that 200 parental interview questionnaires will be completed by March 2001. So far it has been found that parents have tended to clearly remember the postures adopted by their child in early life where, as in the majority of cases, a distinct preference existed. Analysis of the data will not be carried out until March 2001 in order to avoid introducing an element of observer bias in the remaining interviews.

**Reference**

Fulford FE and Brown JK (1976) *Position as a cause of deformity in children with cerebral palsy*. Dev Med Child Neurol.18 (3): 305-314

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**We hope to keep you informed of developments in this research through future editions of Posture and Mobility.**

You up

Me up

You up yet

Me up now

## Being A Full-Time Active Wheelchair User - A Phenomenological Inquiry

S. Kyle, Physiotherapist.
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A qualitative phenomenological study of being a full-time active wheelchair user was conducted with four key participants. The study aimed to generate new knowledge on this phenomenon. It also aimed to contribute to providing a building block for theory construction and generation of testable hypothesis for future studies. By dissemination of the study it aims to begin a process of increasing awareness of those who come into contact with this group of wheelchair users to the nature and meaning of the phenomenon.

Husserlian phenomenology provided the philosophical framework for the study. This aims to ‘go back to the things themselves’; it studies the objects of human experience. It aims to make clear the phenomenon experienced. It wants to avoid a process of superficial description of others’ experience.

Semi-structured interviews were carried out with the four participants. The taped interviews were then transcribed and analysed to draw out key themes. Initial analysis drew out five major themes that were labelled persistence, determination to live life, alertness to barriers and exploitation, core identity and ability to plan and adapt. An integrated description of the meanings and key factors of the phenomenon was then presented.

Initial findings back up what little phenomenological literature there is available in relation to wheelchair users (Bates et al 1993) as well as bringing to light new knowledge. The study demonstrates that by using a phenomenological approach it is possible to draw out key factors of this phenomenon that are not highlighted in current literature. ‘This knowledge can then be built upon in further work. The study brings to light the importance, for those professionals working with this group of wheelchair users, of understanding the phenomenon itself.

Ideas for further work are highlighted, for instance this study deals only with one group of wheelchair users. It would be of interest to investigate other groups and see if key factors of the phenomenon differed; this in turn may have implications for professionals and service delivery.

**Reference:**

Bates P.S. et al (1993) *Assistive Technology and the Newly Disabled Adult: Adaptation to Wheelchair Use*. The Am. J. of Occupational Therapy. 47,1 l,1014-1021

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## Meeting Present And Future Needs A Case Study Of A Teenager With Duchenne’s Muscular Dystrophy

Sue Pimentel, Occupational Therapist
The Occupational Therapy and the
Wheelchair Service Centre,
Dodnor Lane, St. Mary’s Hospital,
Newport, Isle of Wight P030 5TG

Background: P is a 14-year-old boy who lives with his mother and older brother in an adapted bungalow. P had been using a privately funded powered chair, which he had now outgrown. The family were also finding it increasingly difficult to meet the maintenance costs. The mother therefore referred P for an EPIOC assessment. P attends mainstream school. He has a full time support worker at school and is transported by his mother in a Motability funded Renault Kango.

Assessment Procedure: included collecting of information from paediatric occupational therapist and physiotherapist; home visit assessment by the wheelchair service therapist; independent medical examination and eye test by Occupational Health doctor; seating and mobility needs assessment in clinic by the wheelchair therapist, rehabilitation engineer and paediatric occupational therapist; training in the use of the EPIOC and a road safety test by the Road Safety Officer from the local council.

Key Findings: On examination it was found that P weighed over 15 stone; had pseudohypertrophy of the muscles; a posteriorly tilted pelvis; low tone in the trunk and was unable to sit unsupported. He had a marked skin fold on the right side of his chest, indicating possible scoliosis of the spine, convex to the left. He had no pressure areas.

Prescription: Based on the assessment, the following prescription was agreed:

Scandinavian Mobility Harrier to provide a choice of back support and adjustability for future growth and changing needs; Jay 2 cushion for stable base; adjustable swing away thoracic supports allowing access for positioning the sling; custom designed lateral supports and right forearm support; dynamic shoulder straps providing support without reducing forward movement for function and a two point fixing centre pull pelvic strap to position pelvis.

Training and Review: Between assessment and final delivery P had deteriorated making it necessary to change his head support. The school had also changed the desks making a dropped control box necessary. P completed the local EPIOC training and passed the road safety test within two weeks.

Summary: Many boys with Duchenne's Muscular Dystrophy have similar needs to P, but the assessment raises the issue of time. The time taken from referral to final satisfaction with the system was one year. Whilst joint working is good practice and should result in the most suitable prescription, it does lengthen the process. In this case the initial consulting and assessment took four months. The chair and modifications took a further six months before they were ready to be delivered. Is this acceptable when dealing with a deteriorating condition, which depends on timely provision of equipment to maintain optimum function?

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# The Management Of Scoliosis In A Client With A C3/4 Complete Tetraplegia

L. Hills, Occupational Therapist
E.Roberts, Physiotherapist
Spinal Injuries Unit, Royal National
Orthopaedic Hospital Trust,
Brockley Hill, Stanmore, Middlesex,
HA7 4LP.

**Aims and objective for the study**

- To analyse the factors surrounding a scoliosis in a patient with a C3/4 tetraplegia
- To highlight interventions for the management of scoliosis
- To implement appropriate management

**Subject**

A seventeen-year-old C3/4 spinal cord injury patient injured on 23/09199. He is of slim build, approximately 5 ft 10 inches, weighing 7.5 stone.

He was conservatively managed with bed rest at a General Hospital and transferred to Stanmore Spinal Injuries Unit on 22/10/99.

About three months following his admission, he developed a lumbar scoliosis and resulting pelvic obliquity, which made it increasingly difficult to achieve a good seating posture. He complained of pain with his deformity. The patient also had a cervical kyphosis with associated pain. His pelvis showed decreased flexibility, but was not fixed. His spinal curve was flexible but there was some associated shortening of trunk musculature.

**Management interventions**

- Night time positioning programme including mattress considerations, wedges and positioning regime.
- Seating systems were trialed including identification of a suitable wheelchair, cushion, backrest and headrest.
- Trialing of thermoplastic bracing to correct and maintain spinal posture.
- Extensive discussion about pelvic and spinal fusion.

**Results**

After trying extensive seating and positioning systems and a variety of braces, we were unable to manage the progressing curve and pelvic obliquity. Surgery was decided upon at the patient's request.

**Recommendations for future practice/ optimum management**

- Early identification of equipment for assessment and to consider pressure care needs
- Regular monitoring with medical photography from early stages
- Use of video to record detailed assessment to allow analysis
- Early bracing intervention

- Early referral to wheelchair service/special seating to ensure close liaison / joint assessment
- Regular team review
- Carer and staff training - including use of positioning charts
- Regular review by surgical team including x-ray review.

## MAKING CONNECTIONS

P. Aldersea,
Occupational Therapist

Where have we come from? Where are we now? Where are we going? How do we get there? These constitute the main themes of this presentation.

Whilst a brief look at the past gives us some clues regarding the issues that influence change in the areas of disease and disability matters, devolution of wheelchair services in the early 1990s accompanied by a total re-organisation of the NHS triggered the formation of the Posture and Mobility Group and provided the stimulus to set up an accredited Wheelchair Training Programme.

The recent rapid changes, outlined in two government White Papers, (DoH 1997,1998) introduced basic principles of clinical governance, encompassing all aspects of service provision. This in turn has produced a deluge of other papers, regulations, guidelines and position statements. Have we now overdosed on a surplus of information and ground to a halt? Or are we in a position to use new policies as ammunition for moving forward? Evidence suggests that not all guidelines and regulations are appropriately interpreted by professionals, which results in a restrictive outcome for wheelchair users.

Effective communication and networking are central to the efficient progress and development of any service but only if the language, both spoken and written, is relevant and understood by all concerned. How can we, individually and as a group, make sure we connect with the relevant people?

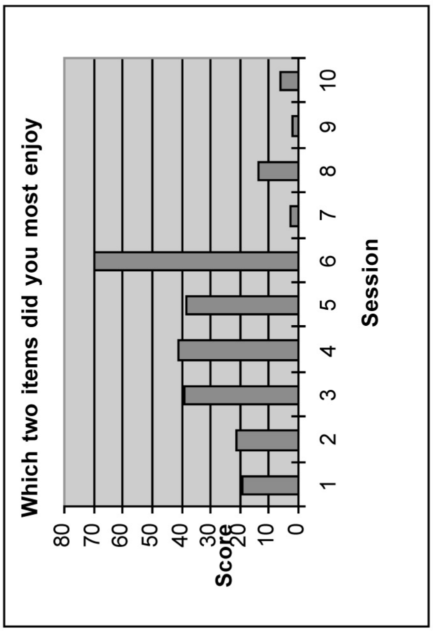
It is hoped that this presentation will encourage PMG members to enter into further discussion when considering changes and development in their services in line with government recommendations.

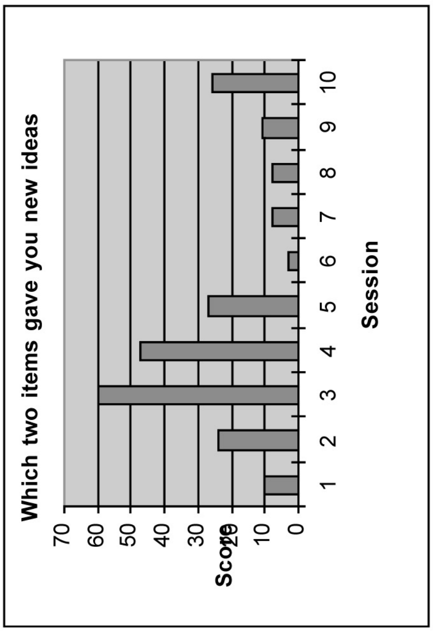
**References**

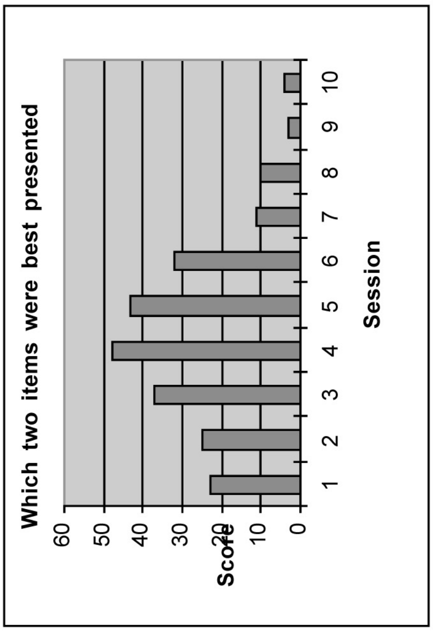
Department of Health (1997) *The New NHS: modern, dependable: a national framework for assessing performance.* London: Stationery Office.

Department of Health (1998) *A first class service: Quality in the new NHS*. London: Stationery Office. http://www.open.gov.uk/doh/newnhs.htm

# Meeting Evaluation for the PMG National Conference: York 20th-21st March 2001


Which two items did you most enjoy


Which two items gave you new ideas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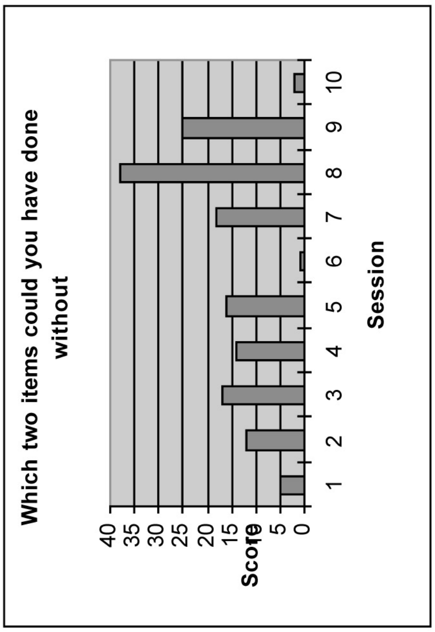
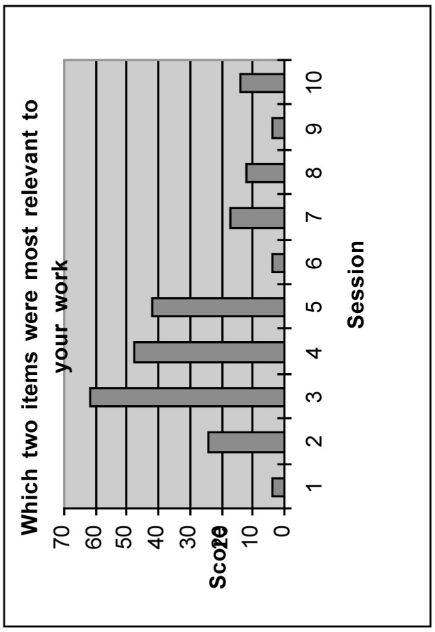
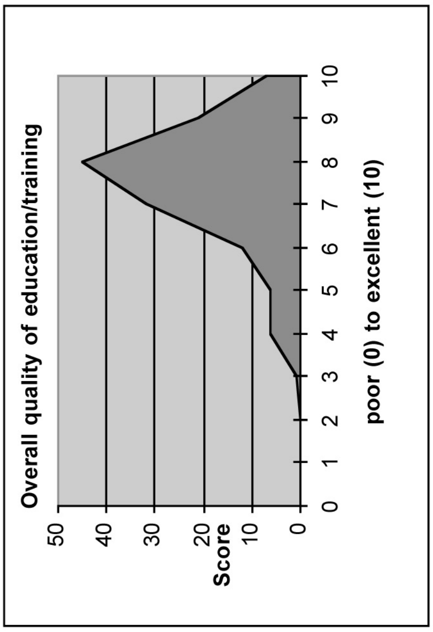

Which two items could you have done without


Which two items were most relevant to your work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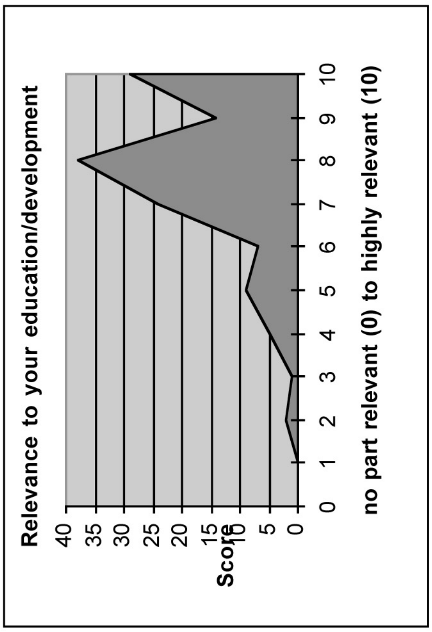
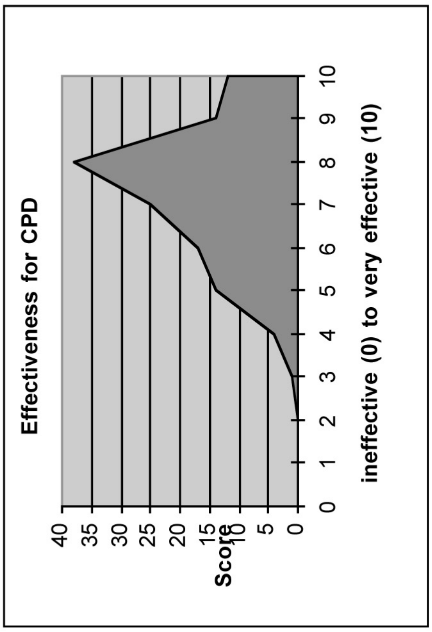
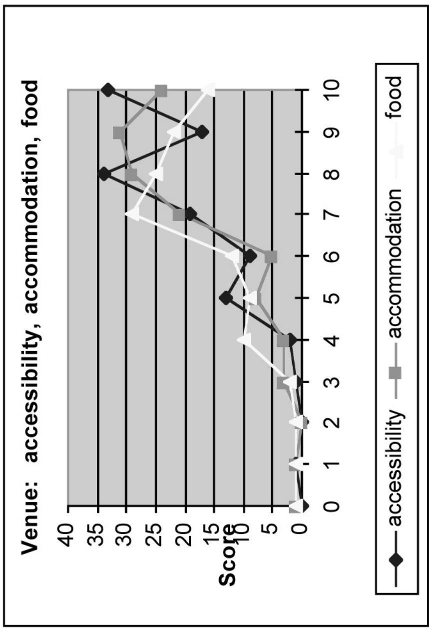

Relevance to your education/development


Effectiveness for CPD


Venue: accessibility, accommodation, food

**The PMG Committee, AGM stand down dates are given below in bold.**

Roy Nelham *Chairman* **2002,** Julia Cunningham *Secretary* **2004**, Barend ter Haar *Treasurer* **2004** Rene Parison **2002,** Simon Fielden **2003,** Phil Swann **2004**, Christine Turner **2004**, Henry Lumley **2004**, Elizabeth White **2004**, Elizabeth Green **2004**, Gordon Mcquilton **2004**, Co-opted: Russ Jewell, Dave Long, Michael Edwards, Anthony Stockton, and Dave Calder for the PMG Guidlines.

The following is intended to give a brief summary of the new committee members and the photos a rough idea of what they look like.

**Dave Long**

I am the Rehab. Engineering Manager for the Special Seating team based at Stanmore, Middx., who provide a Special Seating service to a number of local District Wheelchair Services. I have worked at Stanmore for three years. Prior to this I worked on a research project at King's College Hospital looking into wheelchair services. After leaving University with an Honours degree in Manufacturing Engineering I worked at a day centre for adults with learning difficulties and it was here that I became interested in Rehabilitation Engineering. I am married and have a son who is a year old. I like music of most kinds and have a passion for sports cars (donations gratefully received).

**Martin Moore**

I am a senior Rehabilitation Engineer working for the Wheelchair Service at Bristol DSC and am involved with all aspects of wheelchair and seating provision.

I have been working in the wheelchair scene for nearly 6 years now (how time flies when you're enjoying yourself!). I passed the Kings College Certificate in Rehabilitation Engineering in 1998 and am now working on the University of Greenwich Wheelchair Prescription and Provision Course.

I "fell" into this business in 1995 after making wheelchairs in a rural area of southern Nigeria for 2.5 years (92-95), whilst I was a volunteer with VSO (voluntary services overseas). The wheelchairs were purchased in the main by those disabled by polio or amputee's from TB and the Biafran war.

**Liz White**

I started working in an NHS wheelchair service in East Kent in 1990, with research funding to explore the issues that faced effective service delivery as it was devolved to district level. I liked the work so much that I stayed on as senior OT for nearly 10 years, during which time I completed my PhD and made a number of conference presentations and publications on wheelchair-related topic.

I now work in higher education, but retain my interest in all aspects of wheelchair service provision and lecture on the subject to our pre-registration post-graduate students. I am a founder member of the team who developed the wheelchair training course which is now accredited through Greenwich University and I am also on the research and advisory board of Whizz-kidz.

**Elizabeth Green**

I am a consultant in paediatric rehabilitation at Chailey Heritage Clinical Services and Clinical Director of the Rehabilitation Directorate South Downs Health Trust. The directorate includes adult rehabilitation services and wheelchair services. I have been a member of the postural management research team at Chailey Heritage Clinical Services since the mid 1980's. Our trust is likely to be a Care Trust in the future.

**Russ Jewell**

I am a Biomedical Engineer and have been working at the Oxfordshire Wheelchair Service (based at the Mary Marlborough Centre) for about two years. I am involved with the full spectrum of clinics, but the majority of my time is spent on paediatrics and special seating. I have a degree in Human

Biology from Leeds University and a MSc in Biomedical Engineering from University of Surrey and am currently studying on the Wheelchair Prescription and Provision for Professional Practice, accredited by the University of Greenwich. When not at work I enjoy participating in most sports, especially rugby (injuries permitting!).

**Gordon McQuilton.** Managing Director.of Specialised Orthotic Services Ltd. Which is a business I started about 20 Years ago and it only seems like yesterday, (creek wobble clunk). I am married have 4 children am still sane.I enjoy walking (very slowly) in my spare time.

**Anthony Stockton**

I currently work for Selby and York Primary Care Trust as a Rehabilitation Engineer in the field of Wheelchairs and Seating. My interests include walking, yoga, weight training, computers, D.I.Y., camping and voluntary work for St John Ambulance over the past 10 years. I also like star trek.

**Henry Lumley**

From a background of working in industry, both on the financial side and sales and marketing, I joined the NHS in 1993 following redundancy when I was fortunate enough to be recruited to manage the Disablement Services Centre at Southmead Hospital. The Centre provides a sub regional service covering prosthetics, orthotics, wheelchairs and special seating, environmental controls and community equipment for Bristol and much of the surrounding area. I remain enthusiastic about my work which I readily admit to enjoying (most of the time).

Outside of work, I enjoy my family, most sports, still participating in village cricket with my younger son and the occasional game of golf. I enjoy walking, particularly in the Lake District.

**Michael Edwards**

I am a senior rehabilitation engineer based in York, employed by the York & Selby PCT. I work in the rural county of North Yorkshire which includes the neighbouring Harrogate and Scarborough NHS Trusts. I moved into the NHS 11 years ago from production and automation engineering. Outside work I have been studying Homeopathy for a number of years and I enjoy the countryside and a good guitar (if only I could play!).

## Bursary

The PMG is offering bursaries to students from any background who can demonstrate their attendance will be of benefit to any people with disabilities. The bursary will cover the cost of the conference and travel. The student, for consideration for the bursary, should submit to the Hon Secretary by 29th December 2001 (a) a letter from their educational supervisor confirming that the applicant is a student, and on what course, and (b) up to one A4 page demonstrating the relevance of the meeting to their study/training and the anticipated benefit to clinical practice. The submissions will be judged on standard and relevance. Those receiving a bursary will be requested to provide a report for consideration for publication in the PMG newsletter.

## PMG Prizes Awarded For:

**Free papers:**

Anne Harris "The impact of wheelchair design on the self identity of users"

**Poster presentation:**

Martin Wosencrof "Sinfle switching system for tilt in space chairs"

**Exhibition trail:** Elaine Murray

## Congratulations from the PMG

# POSTURE AND MOBILITY GROUP FOR ENGLAND AND WALES CHAIRMAN'S REPORT TO THE ANNUAL GENERAL MEETING March 21st 2001 AT THE UNIVERSITY OF YORK

## Introduction

Throughout the last year the PMG has grown rapidly in size and now has around 500 members. Clearly it is becoming an even more significant organisation and in order to maintain and improve it's relevance to the members various changes have been discussed throughout the year together with specific pieces of work that need to be undertaken. The pieces of work include pursuing the actions from the Llandudno conference on Working Together, exploring collaborative working with the Scottish Seating and Wheelchair Group, raising the status of the newsletter to a peer reviewed journal, updating the guidelines, preparation of future conferences and establishing two or three venues around which these conferences can rotate, pursuance of charitable status and acting as a voice for the members in issues of service delivery and organisation. All of this requires much effort and one of our proposals to be discussed at this meeting, is an increase in the size of the committee. This will facilitate several working groups to spread the workload. PMG members will no doubt be co-opted to these working parties to spread the load even further.

## Website

We now have an embryo website which you can visit at www.posture-mobility.fsnet.co.uk

Information is gradually being placed on this website and we welcome suggestions for it's development to be of maximum benefit to the members and to others who may access it. I would like to thank David Calder for assisting us with the establishment of this website and we will no doubt be calling on his services again to further develop it.

## Newsletter/Bulletin

There would be significant advantages and some disadvantages in the newsletter becoming a peer reviewed bulletin. Published articles carry more weight and the bulletin would achieve a professional and scientific status that reflects the importance of the services that we provide. The downside would be the loss of an informal communication exchange which may require the publication of a frequent, short Newsletter. The current Newsletter seems to fall between those two types of publication at present. Unfortunately, the committee has not had the time in the past year to pursue these issues. Never the less, the Newsletter continues to inform us but is only as good as the contributions received. I would like to express my thanks to the editorial team who produce this and in particular Phil Swann, the Editor.

## Finance

As the PMG grows so we incur some financial penalties such as the payment of Corporation Tax and the need to register for VAT, which we have now done. Whilst this will allow us to reclaim the VAT that we pay there are administrative penalties and our Treasurer's workload will no doubt increase. More about our Treasurer/Membership Secretary later.

## Charitable Status

The committee have discussed the advantages and disadvantages of the PMG becoming a charity. It would appear that most of the requirements of the Charity Commission are already in place in our constitution and our democratic processes. There are, however, some changes required to our constitution to meet the requirements of charitable status and the committee will need to be Trustees of the charity with some personal responsibility. The committee feel that this is no greater than the current responsibility carried by the committee and it's officers but is made explicit by becoming a charity. The processes, advantages and disadvantages of the PMG being a charity will be discussed further at this conference and in the newsletter. My thanks to Barend ter Haar for taking a lead on this work during the last year.

## Guidelines

The guidelines are now very much out of date and are set to be updated by a working party being convened by David Calder. This work is now set to begin and the working party to execute this has been identified. We would hope to include, in due course, some guidelines on best practice which will be the theme of our next conference in Nottingham in 2002.

## Hub and Spoke Models for Service Delivery

Since the audit commission report "Fully Equipped", discussions about hub and spoke models of service delivery seem to have proliferated. There will be a brief opportunity to explore these at this conference and Robin Luff has summarised a recent presentation by Dr

Dipak Datta. I believe that hub and spoke could be a good model for communication but hubs and spokes go nowhere without a rim! In fact hub and spokes alone can dig themselves into the sand! The rim could represent the working together we all desire and which would facilitate progress. Incidentally, the hub is usually the centre of rotation but goes nowhere especially without a rim! If specialist centres are to be seen at the hub they could be isolated from the "Working Together" represented by the rim. If the specialist services were the spokes then they could be accessed by the local services represented by the hub with the rim representing collaboration between the specialist services. This is the model I think Robin Luff eludes to. Food for thought, wide scope for interpretation and perhaps a lack of clarity about what hub and spoke really means.

### Education

The main PMG conduits for education are the Newsletter and our annual conference. We attempted to organise a satellite workshop preceding the conference to add to the educational value of the event but we were unsuccessful in getting a notable presenter from the USA. This is still on our agenda as a desirable event either before or immediately after our conference to address a specific subject such as client assessment. We would welcome suggestions from the membership as to appropriate one day or half day work shop sessions linked to our annual conference. With a larger committee, subject to agreement at the AGM, we would hope to be able to explore regional PMG conferences, seminars or workshops.

Again at this conference we are able to offer subsidised book purchase for our members to the value of £30.00. I believe the educational value offered by membership of the PMG far outweighs the costs involved. Please spread the word to your colleagues outside of the wheelchair and seating services - particularly therapists who work in the community. By bringing our colleagues to our conference we will be better able to learn how to work more collaboratively.

### Committee

I am again indebted to all of the committee members for the work they have undertaken during the year. We each have experienced personal and professional pressures which have prevented us from doing as much as we anticipated or wished. Emma Parry has had to resign from the committee after only one year because of such pressures. I would like to thank Emma for the knowledgeable contribution that she has made during the year and I regret that she has had to leave prematurely.

Robin Luff also stands down this year after many years of excellent service. I am very grateful to Robin for his significant contribution during the last two years of my chairmanship and in particular his knowledge of the impact of clinical governance and how it can be used to improve our services.

Other committee members standing down but also standing for re-election are Julia Cunningham, our Secretary, Barend ter Haar, our Treasurer and Membership Secretary, Christine Turner and Phil Swann who has successfully led the production and publishing of our two Newsletters whilst undergoing a major change in his role from health service to industry.

Once again, BES Rehab have been chosen as our conference organisers this year and as a result, Barend ter Haar has had a tremendous work load as Treasurer and Membership Secretary as well as leading the conference organising team. It is mainly due to Barend's efforts that the PMG has around 500 members and has such a well organised conference despite necessary last minute changes. Throughout the year we have benefited from free access to the BES mailing list which has enabled PMG information to be sent out with BES mail shots. Unfortunately, this had led to some misinterpretation that BES Rehab have benefited from free advertising with PMG mail shots when in fact the reverse is true. Once again, I extend my sincere gratitude to Barend as Treasurer and Membership Secretary and to his very professional approach to organising our conferences.

### Aldersea Lecture

As most of you will now know, Patsy Aldersea has finally retired - at least from the PMG Committee. I am not convinced that Patsy will ever retire completely! Patsy has quietly and diligently set standards for clinical practice, acted as advocate for clients as well as services and service providers and in particular has been a model of networking for us all. Is there anybody that Patsy doesn't know and is there anything happening that she doesn't know about? I doubt it and I have yet to find it! Thank you for all you have done.

To mark Patsy's achievements and her significant contribution to our field of activity we have decided to inaugurate the Aldersea lecture at our conference. The first lecture will, of course, be delivered by Patsy at this conference. At future conferences we will invite colleagues who have made a significant contribution to communication, networking and standards of professional practice to deliver the Aldersea lecture as a tribute to Patsy's standard setting career.

............... and finally

Please don't forget that the committee can only act on your behalf if we know what you want. Please keep us informed of the specific ways in which you believe the PMG can best meet it's aims and objectives and to support excellence in clinical practice in all aspects of posture and mobility. We look forward to hearing from you at this conference in letters to the editor of the newsletter and communications with the committee. In due course, we will enable this via the website.

**Roy Nelham**

*Chairman*

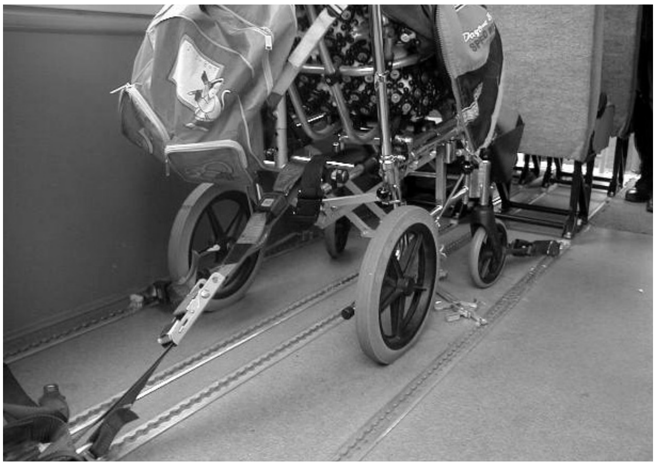
Roy Nelham

# Post Bag

## Does a 'crash-tested' wheelchair guarantee your child's safety on transport?

Transport services constantly demand that wheelchair services provide wheelchair users with 'transport approved' or 'crash-tested' equipment. Many wheelchair services do their best to provide wheelchairs that have been crash-tested, particularly when prescribing new or replacement equipment. However, there is no guarantee that passengers in wheelchairs certified as 'crash-tested' or 'transport approved' are any safer in such equipment than those who are not.

People in wheelchairs have been carried around on transport vehicles for a very long time. Any reported cases of serious injuries or fatalities to occupants resulting from road accidents involving such vehicles due to wheelchair not being a crash-tested model, are probably nil. More often than not, serious injuries or fatalities occur, not because of the lack of structural integrity of the wheelchair, but because the equipment is either not adequately tied down or is tied down in an inappropriate and dangerous manner.



It is all very well for nursing homes, institutions and transport managers who deal with wheelchair users to request or sometimes demand the wheelchair services to provide mobility equipment featuring all the latest safety features. Indeed, in some cases, transport services have refused to transport wheelchair users unless they have a new or crash-tested wheelchair. They do not seem to realize that they must first get their own house in order and ensure conformity with safety guidelines relating to carrying wheelchair passengers on transport vehicles. Otherwise, it is a totally fruitless exercise that costs the tax payer a small fortune, yet puts the wheelchair users' lives at risk.

The photographic evidence above shows clearly the dangerous or potentially lethal methods recently seen in use by one of the local transport buses to anchor a buggy (fitted with 4-point tie-down hooks with instructions on use affixed to frame) and also a transit wheelchair interfaced with a matrix seat.

Who has the duty of care in these cases? Wheelchair services have a remit to provide mobility equipment. Transport services have a remit to transport their passengers in a safe manner. The way forward must surely be for wheelchair services and transport services to work together to assess the risks and ensure they are within acceptable limits. In this way, we can put an end to similar dangerous practices, which I suspect are prevalent up and down the country today.

**Keith De Silva,**

*Rehabilitation Engineer, Rehabilitation Engineering Division, Kings*

## Re: UK wide provision for children

As a charity providing mobility equipment to children under 18 who are unable to obtain such items from the statutory services, I would like to share with your readers some observations my team have from about the UK, which may lead to a wider debate on the subjects.

1. **Manual wheelchairs for powered wheelchair users.** A number of NHS wheelchair services do not provide a back-up manual wheelchair to users who are eligible for a powered model.

   ***Question:*** What do these users do while their powered wheelchair is not working? What do these users do when ambulance services will not carry their powered model to hospital appointments? What do these users do if they are unwell and unable to drive their powered wheelchair for any length of time but need to leave home for an appointment?

2. **Partnerships with professional workers.** The National Health Service and Community Care Act 1990 and the Children's Act 1989 gave a central place to the concept of 'partnerships', between families and service providers. (The NHS plan 2000 also promotes partnership working). Services, it was then said, should be needs led rather than resource-led. Parents and carers should be enabled to say what support services will best meet their needs in their particular circumstances.

   Children are regularly applying to Whizz-Kidz as they do not meet the local criteria for provision or they are too young. Yet in many cases an assessment has not been carried out and their needs identified. "Unmet needs" it appears, are rarely reported to senior managers and Commissioners.

   ***Question:*** Are professional health staff employed to be "gate-keepers" or are they employed to assess individuals and identify, with them, their needs?

3. **Assessing for and meeting identified need.** Many NHS wheelchair services clearly tell us that they do not issue "X". For example this could be; tilt in space, head rests for the prescribed system for transportation purposes, switches, attendant controls.

   ***Question:*** How can a health professional assess for need and yet have blanket statements in their service, which say they do not provide X.

4. **Powered mobility for younger children.** Many services do not provide powered wheelchairs for children under 10 years of age as they "will not be fully independent and safe using the equipment outdoors".

   ***Question:*** How are children expected to learn to be independent and safe if they are never given the equipment to learn with? How many of the readers' children were fully independent and safe on their bikes/trikes at this age?

   How many readers have searched for the evidence in the literature to back up such statements?

5. The NHS plan (2000) promotes joint working between agencies.

   ***Question:*** How many wheelchair services now meet the needs of children by working with other agencies such as education and social services .

6. No UK citizen is allowed to wait more than 18 months for an operation.

   ***Question:*** Why can disabled children wait more than this period for a powered wheelchair assessment?

7. The Family Fund Trust funds a variety of needs for families of severity disabled children with an income of less than £20,300 (2001 ) and less than £8,000 in savings.

   ***Question:*** How many readers know that this fund may be able to help families with holidays or leisure activities, driving lessons for main carer, play equipment such as trikes, amongst other things? And that they have £22m to spend! (www.familyfundtrust.org.uk).

8. Many approved repairers only deal with Control Dynamics

   ***Question:*** Does this system meet all clinical needs?

I will very much look forward to any comments from you, or I receive from your readers on these questions.

Yours sincerely

Ros Ham
*Director of Children's Services*

Dear Ron. PMG Committee & Members,

I am amazed and delighted to receive the Travel Vouchers on top of the other superb gift. I am now busy planning where they are to be spent. Not on the ski-slopes with a cello on my back as the person on this card has chosen to do!

Possibly Hong Kong & up into China - or India & up to the Himalayan foothills - or maybe somewhere else

Difficult making a decision & if I take too long it may be a SAGA day trip across the Mersey!!

But — very many thanks for your generosity. It's really great & I'll let you know what the final choice will be.

The eagle has landed on the Lakeland Slate fire surround - he looks magnificent!

Thank you all & hope to see you next Spring.

Best wishes

Patsy.

Dear PMG members,

I am overwhelmed by your generosity and find it difficult to know how to thank you all: firstly for the beautiful cut glass eagle ornament, the lovely flowers and card which i received in York, and secondly for the recently received travel tokens. I am speechless!! Thank you all very much indeed.

Where to travel to is now the question. There is no shortage of suggestions and a family barbecue has been arranged to ease the decision making process - I will keep you posted.

A final special thank you to the committee for honouring me with the 'Aldersea Lecture'. It has been a tremendous privilege working with so many committed (and entertaining) colleagues. Thank you all for your support and for the opportunities this has given me. I look forward to seeing you all in Nottingham next year.

Best wishes and a multitude of thanks,

Patsy Aldersea

# Notice Board

| Date | Location | Title | Contact |
|---|---|---|---|
| **October 2001** | | | |
| 10 | London | Trikes and Bikes study day | tel. 02072336600 |
| 22 | London | Whizz Kidz **Free2B** Conference | tel. 02072336600 |
| **November 2001** | | | |
| 5 - 6 | Birmingham | RAATE | tel. 020 7346 1650 |
| 15 - 16 | Pitlochry | Scottish Seating and Wheelchair Group | Alison Laing, Woodend Hospital, Eday Rd, Aberdeen, AB15 6LS |
| **April 2002** | | | |
| **15 - 16** | **Nottingham** | **National Conference of the PMG** | **tel. 01223 882105** |
| **June 2002** | | | |
| 11 & 14 | Brighton | College of OT's Annual Conference | tel. 02089770011<br>email: cot@hamptonmedical.com |

## Standards Information

## Look up:

**www.wheelchairstandards.pitt.edu**

A well attended seminar on seating standards was held in Birmingham on the 31st of August. This was a joint venture by the BHTA and PMG. Chaired by Ray Hodgkinson, the morning was given to short presentations. Alan Lynch kicked off by summarising the standards process followed by Barend ter Haar who explained part 1, Martin Ferguson-Pell part 2, Roy Nelham part 3, Bob Appleyard part 4 and David Hull covered the rest listed opposite. After lunch the delegates split into five groups to review each of the standards. All proposed changes will be reviewed by expert groups and a second draft will then be published for comment in 2002.

This was an effective way of generating comment and stimulating debate. Everyone felt satisfied at having contributed to the development of standards that will effect the way we work in future.

All the standards can be viewed on the website above, the ones dealt with at Birmingham were:

Seating Standard Part 1:

**Definitions of body and seat dimensions.**

Seating Standard Part 2:

**Tissue integrity management devices.**

Seating Standard Part 3:

**Postural support devices - test methods for static, impact and repeated load strength.**

Seating Standard Part 4:

**Seating devices for use in motor vehicles.**

**ISO10542:** Wheelchair Tie down and Occupant Restraints, Parts 1-4

**ISO7176-19:** Wheelchairs: Wheeled Mobility Devices for Use in Motor Vehicles

**ISO7176-20:** relates to stand up wheelchairs

**ISO7176-24:** relates to stair climbing devices

## WEB WATCH

Here's the addresses of some web sites worth a look:

**www.posture-mobility.fsnet.co.uk**b PMG web site, have a look and use the feed back to help develop the site further.

**www.whizz-kidz.org.uk** - Whizz Kidz web site

**www.resna.org -** Resna home page

**www.raate.org.uk -** Recent Advances in Assistive Technology and Engineering

**www.fastuk.org** - on-line database of assistive technology research and development.

If you're surfing the net and come across an interesting web site related to Posture and Mobility and would like to share with the PMG, email the address to PhilSwannptmy@aol.com. Sensible sites only please!

# Literature Review

## Disability, Oppression and Public Policy

Is the title of a small study concerned with disabled people's perspective on the professionals' response to a statutory policy; The Manual Handling, Operations Regulations (MHOR) l992.

Some of the themes of the research are as follows, it:

- Suggests alternative approaches to the issue of good practice in manual handling
- Promotes disabled people's ideas of good practice in manual handling,
- Reviews disability oppression in the context of British society
- Explores the mechanisms of professional power
- Demonstrates that disabled people experience disability oppression in British society
- Identifies evidence of institutional oppression of disabled people
- Argues for civil rights legislation to protect disabled people from oppressive experience

The move towards evidence-based practice encourages practitioners to keep up to-date with research in their area of work in order to ensure their practice is based on facts rather than values. In the Long-term this increases the ability of organisations to be anti-oppressive. In addition, the Disability Rights Commission came into effect this April and the implementation of the Disability Discrimination Act 1995 and the Human Rights Act 1998 make it expedient for all organisations to be planning with these issues high on the agenda. "Disability, Oppression and Public Policy' is the first research on the MHOR 1992 from a disability rights perspective and is essential reading for practitioners in health, education and social services and those interested in learning more about the wider political and social context.

You can obtain a copy of the full document from the research author Sue Cunningham PO Box 275 Keighley LDO BD22 9YS for £9.95 including postage and packing. Please make cheques payable to *'Sue Cunningham'.*

*Note, whilst not strictly a review this is a useful summary of the content of this study.*

### Dilbert's Rules of Order - Part two.

**Ever had one of those days...?**

9 I don't suffer from stress. I am a carrier.
10 You are slower than a herd of turtles stampeding through peanut butter.
11 Everybody is somebody else's weirdo.
12 Never argue with an idiot. They drag you down to their level, then beat you with experience.
13 A pat on the back is only a few centimetres from a kick in the butt.
14 Don't be irreplaceable - if you can't be replaced, you can't be promoted.
15 After any salary raise you will have less money at the end of the month than you did before.
16 The more crap you put up with, the more crap you are going to get.
17 you can go anywhere you want if you look serious and carry a clipboard.
18 People who go to conferences are the ones who shouldn't.
19 If it weren't for the last minute, nothing would get done.
20 When you don't know what to do, walk fast and look worried.
21 Following the rules will not get the job done.
22 When confronted by a difficult problem, you can solve it more easily by reducing it to the question, "How would the Lone Ranger handle this?"

**and finally...**

23 Always take on more than you can possibly handle. John Suchet.

# Education & Training

## A double module short course:
## Posture Management for People with Complex Disabilities

This is a validated, collaborative course between Oxford Brookes University and Mary Marlborough Centre, Nuffield Orthopaedic Centre NHS Trust. It is a double module short course on successful completion of which participants are accredited with 40 CATS points at Master's Level. The course consists of three taught weeks, at Mary Marlborough Centre.

Teaching and learning episodes include didactic sessions, workshops, small-group work, tutorials and practical sessions on clinical issues related to the course. Self-directed learning (during the 10 weeks before the start of the course and in the 10 weeks between weeks one and two and two and three) will include practice in your workplace, client assessments, reading, assignments, a project and a visit on which a report is written.

One course is run in each academic year. It is appropriate for Occupational Therapists, Physiotherapists and other Health Care Professionals whose work encompasses people with complex disability.

**Course philosophy**

There are an increasing number of people in this category of severe disability who present with complex problems, suggesting a need for expertise in this field. In an effort to address the difficulties presented by this client group, a relatively new field of medicine is developing.

Many people with severe impairment are, or become, non-ambulant with significant posture deficit. Inappropriate posture management can lead to the development of secondary problems, which may include deformity and tissue damage. Measures taken to deal with these problems are extremely costly in terms of the money, time and special care required.

The problems faced by people with severe disabilities impinge upon many aspects of their life and the lives of their carers and families. In order to maximise functional ability and minimise the secondary problems arising as a result of posture impairment, the issues should be addressed in terms of an on-going 24-hour management programme. If such a programme is to succeed, it should be considered in the context of the disabled person's physical, social, psychological and environmental circumstances, i.e. posture for daily living should be holistically addressed and be appropriate to the social and environmental circumstances of all concerned. We believe that correct management will not only benefit the individual in terms of his or her quality of life but benefit service provision in terms of cost and effort of care.

Attempting to resolve the range of difficulties presented requires specialist knowledge and skill. Thus there is an urgent need for education and training at an advanced level for therapists (and others) working with people presenting with severe and complex posture problems. This course seeks to meet that need through the in-depth study of posture.

To inform the issues of continuing professional development, evidence based health care and clinical governance, students on the course are encouraged to develop their critical thinking and research capability and are offered opportunities to examine the evidence for interventions in the management of posture for people with complex disabilities.

The course provides the opportunity to:

- expand knowledge of biomechanics and update knowledge of the anatomy and physiology of the neuro-motor system.
- develop a deeper understanding of what is meant by posture and the effect of impairment upon it and the implications for clinical rehabilitation in its widest sense e.g. the treatment costs and pain of pressure sores.
- practise and critically review the process and the outcomes of the assessment of the posture of people with complex disabilities
- expand and develop a variety of approaches to the management of posture for people with severe disabilities.
- critically analyse alternative courses of action and justify, in holistic terms, chosen interventions.

The course organisers are Pauline Pope, Consultant in Disability Therapy, Mary Marlborough Centre; Wendy Murphy, Therapy Education Co-ordinator, Nuffield Orthopaedic Centre and Janet Wells, Education and Training Consultant, London.

For further details, please contact: Kim Annelly, Course Administrator, Mary Marlborough Disability Centre, Nuffield Orthopaedic Centre, Windmill Road, Headington Oxford OX3 7LD. Telephone 01865-227879. e-mail: annely.kim@noc.anglox.nhs.co.uk

## Whizz-Kidz wheelchair training scheme

Whizz-Kidz has been awarded a section 64 grant by the Department of Health to pilot a national standardised programme for under 18s in wheelchair mobility skills. The grant, worth £133,500 over 3 years, will enable Whizz-Kidz to develop a high quality programme of training for children and young people to enable them to gain the maximum benefit from their mobility equipment and increase their independence.

The pilot programmes will be tailored to three different age groups, ensuring that the training relates to the children's development and educational milestones. Whizz-Kidz also plans to work with and seek endorsement from RoSPA, and to work in partnership with road safety officers and educational establishments in each local area that the project is run.

I am currently researching wheelchair training provi-

Please contact: Sarah Jefkins, Wheelchair Services Project Officer (D of H) at Whizz-Kidz, 1 Warwick Row, London SW1E 5ER or email s.jefkins@whizz-kidz.org.uk.

## University of Greenwhich

Credit rated course Level II starting on the 8th Oct. **Assessment and Recommendation for personal transport needs.** This is a distance learning course with study blocks and is part of the University of Greenwhich mobility and wheelchair training programme. A first degree is not required as an entry requirement. The course is designed for therapists, helpers, administrators, information providers, driving instructors, assessors, trainers, designers, technicians and retailers

r an information