POSTURE &
MOBILITY
GROUP

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Cover Page:
Llandudno

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The next issue of Posture & Mobility will be in **Dec. 2000**. The deadline for this issue is the **4th 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) on disk.

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Editorial

We are constantly being reminded that undertaking clinical audit with regular monitoring of all service provision within the NHS, is an essential element of our practice. It enables us to identify areas of weakness and can provide pointers for change. Whilst recognising the value of audit in times of stress, staff shortage and high demand, it is all too often viewed as an irksome task - to be avoided whenever possible. After all, we all know that everyone wants a lighter wheelchair. Our clients, their carers, as well as colleagues outside the service, constantly remind us of this need. One would therefore expect this requirement to top the list in any user survey. Curiously, and perhaps of particular interest to wheelchair providers, `Chair too heavy' came in at number 7 in the sample audit undertaken by the National Audit Commission as part of their fact finding exercise for the report, "Fully Equipped" (2000). Four of the six top problems highlighted by wheelchair users in fact related to lack of instruction both practical and written. The results published in this report are based on a small sample of the total user population.. In fact one could dismiss the report on the basis that only a minority were consulted and comfort ourselves with the thought that: `our service is not like that'. Whilst many feel the report to be critical of their work, this is certainly not the intention. Perhaps it shows how defensive we have become based on our inability to provide the appropriate equipment required to fully meet our clients' needs. The audit commission report should be closely studied. It is a lengthy document but by using the `Briefing' section issued to delegates at the Llandudno conference, one can quickly find relevant statements under `key issues' on which to base discussion with senior management. Equipment services provide the gateway to independence, dignity....... 'Proper equipment is central to effective rehabilitation'. Get in there and make sure your senior manager has seen the report and responds to the message. `Pressures are building; demand is increasing;

users ‘ expectations are rising.... ‘. These statements can be quoted when pressing for adequate resources - budgets, staff and facilities. `Staff work in isolation; ‚Senior managers neglect equipment services; many services suffer from lack of clinical leadership’. Do not feel threatened but encouraged that the audit commission has identified these critical areas which need tackling. You may not agree with all their conclusions and recommendations, but use them for debate, supported by your own figures and information.. Don’t let this opportunity pass you by. Your senior manager or commissioner may appear to have a blind spot when wheelchairs enter the arena. `Wheelchairs are not sexy enough to be a high priority’ one therapist was told by a GP. What a `wally’ ! - and such arrogant ignorance . Is this the attitude you would hope to see in a professional who may well be holding the purse strings for your service in the not too distant future? The report is merely a `taster’. It is intended to encourage Trusts to commission a full audit of local equipment provision and hopefully raise the profile, funding and quality of provision.

Conference evaluation sheets are also a form of audit. They guide the organisers when planning future events. Only 81 delegates took the trouble to complete the `audit’ on the Llandudno conference - we will try to respond appropriately. To the remaining 197 - Do you have no comments? no views? no ideas for future meetings? Too late for evaluation, but perhaps something in the form of an article, comment, or simply a letter would not go amiss. Just a sign - anything to show that you are there and keen to support your professional group.

Patsy Aldersea

Assistant Editor

Letter from the Chairman

The Llandudno Conference was the culmination of my first year as your Chairman. My report for the year was presented at the AGM and is reproduced elsewhere in this Newsletter. I will, therefore, be brief here and avoid duplication of that report save to say that I would like to reinforce my thanks to the full committee, whose efforts made the conference the success it was.

We have learned several lessons from our own personal experiences of the conference and your valuable feedback which has now been analysed. We are taking these lessons on board in the planning of our Nottingham conference, and are constructing the programme to include a greater clinical and technical component. The content will, of course, be dependant on those of you who decide to submit papers and presentations. The conference will be held on 2nd and 3rd April 2001 with the overall title of “Children of Today: Adults of Tomorrow,” indicating the investment in the provision of services to children to maximise ability in adulthood.

The workshop sessions at Llandudno were addressing solutions to what we perceived as the barriers to “joined up working” or “working together”. The summary of the workshops is published in this Newsletter and a subgroup of your committee is planning a series of meetings in order to establish a way towards improved seamless services to our client group; considering the whole person and not just a sitting person or a wheelchair user. This is not, of course, to suggest that everybody should do everything but that we facilitate each other to do what we have to do.

As I write this letter I am learning more about the NHS changes and the developing situation with Primary Care Trusts. The major changes taking place within many existing NHS Trusts provide us with an opportunity to influence change in favour of our client group’s requirements. In particular the opportunity to invest in the seamless approach which Primary Care Trusts aim to address by ensuring that we keep up to date and in contact with these rapidly developing situations to hopefully influence change for the better. Such opportunities arise very infrequently and I strongly urge you to discover the local planning that is currently taking place in order to see if we can achieve the seamless services as required as indicated at Llandudno. The outcome of the workshops will be disseminated widely to help with this process.

Finally, I would like to warmly welcome our two new committee members, Emma Parry and Simon Fielden, who have attended their first committee meeting and I look forward to their valuable contribution to our Group over the next few years.

Roy Nelham

Chairman

Roy Nelham

Helping Gravity Help You: Part 2

Using secondary supports effectively

In volume 9 of Posture & Mobility I shared the first two parts of Tom Hetzel's course: 'Helping Gravity Help You'. In that issue we covered how to assess clients to provide the most conservative and intervention-free seating and positioning solutions possible. We looked at how far we can go to suit clients as effectively as possible without resorting to secondary supports. In this article I will be looking at how to use secondary supports effectively, when we have gone as far as we can without them, and there is still need for additional intervention. This made up the third part of Tom's course. We will be covering separately stabilisation of the pelvis, the foot, and the upper body.

What makes a good secondary support?

A good secondary support should aid stabilisation rather than create restraint. In providing the stabilisation, the support should allow for the maximisation of mobility and function, whilst being designed to minimise any risk to tissue integrity. When selecting a secondary support one should be looking for strength, adjustability, padding, and facility for maximising dynamic action, in the first place, and design for the required function in the second.

The traditional piece of plain webbing provides little of these characteristics! First, the webbing tends to fold over and dig into soft tissues; secondly, it provides little adjustability; thirdly, it has tended to be fixed to the chair in a standard position, irrespective of the postural correction being sought.

In contrast, modern belts and harnesses have padding which both stops the webbing from folding over, and spreads the load on the belt over a wider area, to optimise client comfort and tissue integrity. Likewise, modern belts come with a tightening device which allows for easy fastening of the buckles without having to fiddle around in the clients clothing, a gentle pull bringing the belt to the required position. The positioning of the fulcrum point for the tightening mechanism can be chosen by selecting the appropriate belt, according to the pelvic positioning correction needed (see below). The closure selected can take into account the user's or carer's abilities and requirements; (e.g. elastic buckles should be selected for use on shower chairs). Finally, the belt can be attached by screwing into the chair metalwork, by wrapping the webbing around the metalwork, or by attachment to P-clips which fasten around the metalwork.

Pelvic stabilisation

The aim of a secondary support is that by limiting freedom in one area there is a measurable objective of freeing another area. For example, if by stabilising the pelvis, the head and neck stay in alignment resulting in the individual finding it easier to swallow, the number of occasions when aspiration is necessary can be measured as reduced.

When approaching pelvic stabilisation, as with all secondary supports:

1. It is nearly impossible to achieve effective stabilisation without a firm back support.
2. The more aggressive the primary support structures, the more aggressive the secondary support will need to be.
3. The greater the ease of use of the secondary support, the better compliance from the user and carers.
4. The secondary supports are the least expensive components of a wheelchair and its seating system, but are arguably the most important

When choosing a pelvic secondary support, one has a choice of a rigid or a flexible device. For the rigid devices, pelvic retractors and sub-ASIS devices are used proximally, or knee blocks distally.

At the knees, a knee block makes mechanical sense for holding the pelvis in place. However, they should only be used where the foot and pelvis are held firmly in place, where there is no risk of subluxation of the hip or knee joints, and where they can be positioned to provide some abduction and lateral rotation of the leg. A fixed device also tends to place a lot of force over a small area, i.e. producing high localised pressure.

Therefore, for most clients a flexible device (usually a belt) will give greater comfort and safety, while providing an effective postural control provided that the device is mounted correctly. The appropriate choice of belt depends on the pelvic tendency you are trying to correct – Posterior Tilt, Anterior Tilt, Obliquity and

Asymmetry, Rotation. The most common of these is the posterior tendency.

Correction of Posterior Tilt

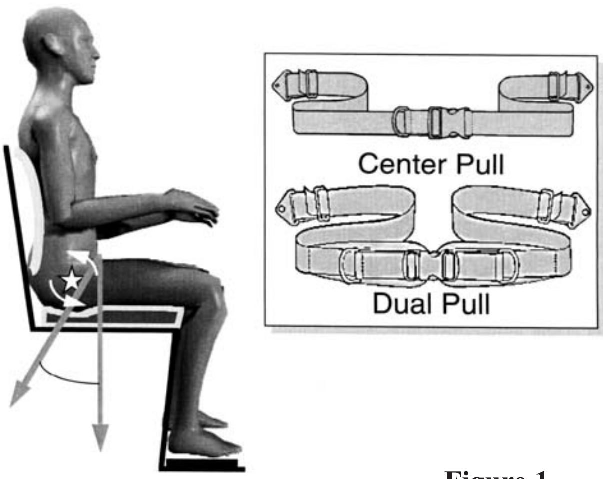


Figure 1

For correction of a posterior tendency, figure 1, first of all it is important that there is an appropriate back support pushing against the posterior superior iliac crests. Since the axis of rotation is the hip joint, to stop the pelvis slipping forward, a centre or dual pull belt positioned over the upper thigh is needed. The straps of the belt need to be positioned anterior to (in front of) and inferior to (below) the greater trochanters. Hint: facing your client when he/she is positioned in his/her chair, place your hands on his/her thigh to push your client's pelvis well into the back of the seat. At this point your fingers will be pointing to the region of the horizontal seat canvas supports where best to attach the belt.

Note: attaching the belt to the right angle between the backrest and the seat will have the belt behind the trochanters with the result that the client slips under the belt. In addition, the belt digs into the abdominal soft tissues. This fastening position is to be avoided. Unfortunately, in the community, there are all too many examples of plain webbing that has been fixed in this position, with the concomitant bad positioning and discomfort to the user.

Correction of Anterior Tilt

For correction of an anterior tendency, figure 2, the belt should be positioned parallel to the seat base and attached to the backrest uprights, thus pulling straight back, to block the tendency. Again, a back support to the superior posterior iliac crests is needed, so that the force from the belt has something to pull against. A four point belt is recommended, with the thinner strap positioned to stop the wider part of the belt riding up.

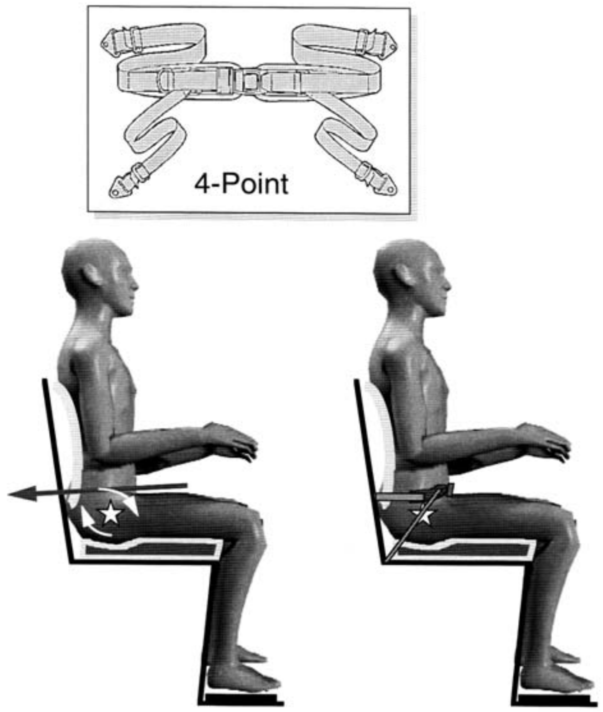


Figure 2

Do watch out for redness at the ASISs.

Powered tilt in space will also help those with an anterior tendency. For MD boys it is important to bring in this facility early so that the upper body musculature can be accustomed to the different positions. If introduced later, when absolutely needed, the clients will probably find it difficult to breathe in the tilted back position. One should also remember that multi-positional seating is to provide for multi-functions, and not necessarily for postural goals. One or two of the positions may also give good posture, and these can be returned to after achieving the functional aim.

Correction of Obliquity and Asymmetry

To correct pelvic obliquity, figure 3, a rear pull belt is recommended. The leverage from the tightening mechanism applied nearer to the belt mounting point gives a strong mechanical advantage: this position is helpful in pulling the pelvis into the required position and providing the required elongation of that side of the individual. (Hint: tighten the belt on the 'lower' side first, before tightening the other side to achieve the required elongation.) The mounting positions for the webbing will depend on whether the associated tendency is for posterior or anterior tilt (see above), or a mixture of both.

Correction of Rotation

For rotation of the pelvis, figure 4, the axis of rotation is in the horizontal plane. A rear pull, four point belt

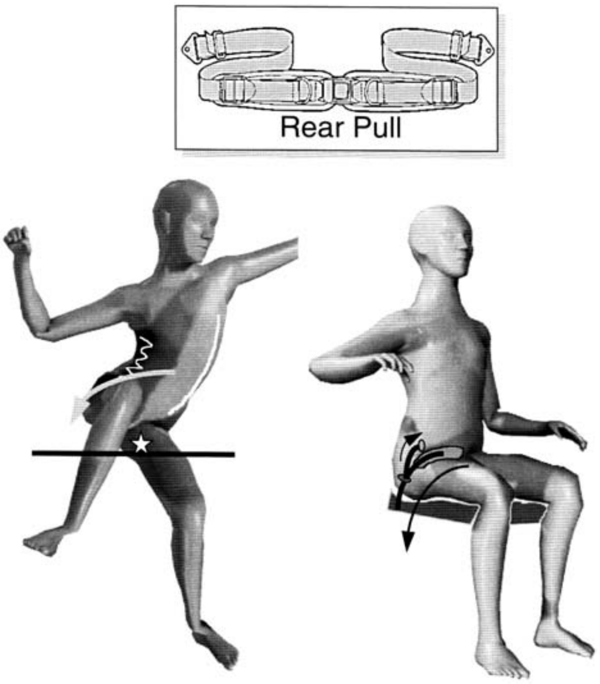


Figure 3

will provide the leverage to counter this. It may not always be possible to work out bio-mechanically the best mounting positions for the belt. However, if you place your hands on either side of the pelvis in a position to push the pelvis into the required position, your fingers will be pointing at the optimal mounting point. Do remember that if you only need a single strap of webbing on one side, then you can cut off the smaller strap on that side, and turn the 4 point belt into a 3 point belt.

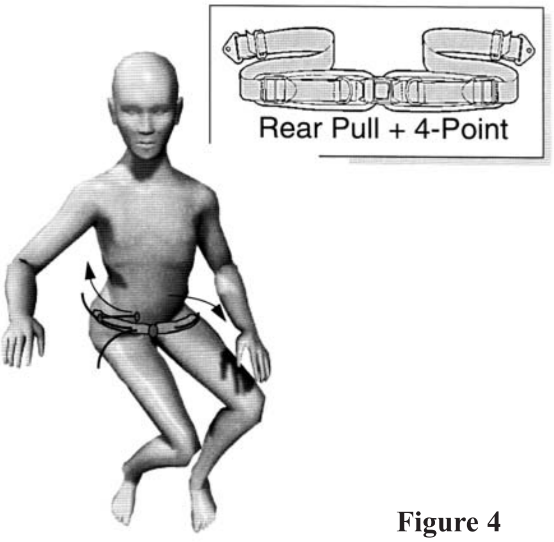


Figure 4

Stabilisation of the Foot

Why should we try to stabilise the feet? Clearly, we do not want to get stabilisation confused with restraint. The best indicators that support distal stabilisation of the foot are that they should improve proximal control of the pelvis and trunk. Secondly, they should thereby improve distal function of the upper extremities, head and neck.

As ever, our concern should be for joint stability. Thus, if we are to fix the pelvis and the feet, we must make sure we do not compromise the knees. For example, if there is a tendency for windsweeping, then lateral supports for the knee are called for.

Accounting for Movement Patterns

The advantages and positioning of foot stabilisation should take into account movement patterns. **Extension patterns** can be broken up by stabilising the pelvis and the feet: the individual will then extend into the primary supports, figure 5, and will therefore be safe.

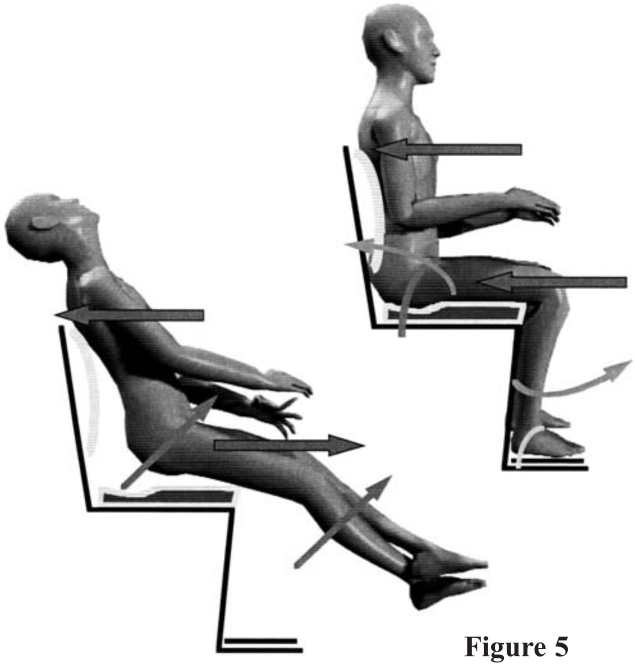


Figure 5

However, for **leg flexion** the lower leg tends to be placed at the end range of the hamstrings, and therefore at flexion the individual will pull him/herself out of the supports, figure 6. Ideally, the feet should be placed as far back as possible, so that the force of the flexion can be taken up in part through the hamstrings. After all, the wheelchair should not be considered as the therapy tool for controlling hamstring contractures! For hip flexion, be careful that the client is not placed too far forward with respect to the wheels, or else the flexion will bring the client forward, and the chair on top of him/her.

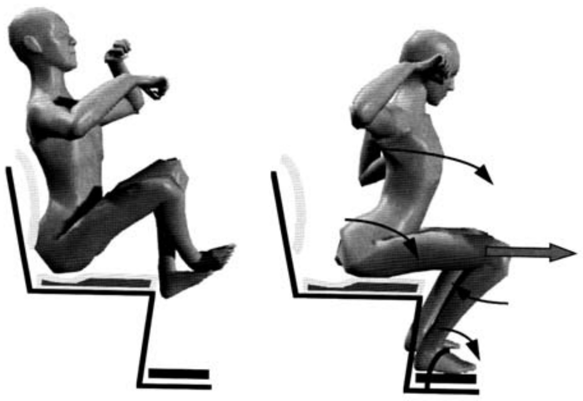


Figure 6

To control the foot and ankle, a good orthosis is the best answer. Foot support accessories, such as Ankle Huggers™, aid control of the knee and hip, and what they do is to control rather than block the distal portion of the body.

Ankle Huggers™, figure 7, are a particularly valuable tool, in that you can control the amount of movement of the feet by the length and angle at which the side pieces are attached to the foot support. By supporting around the ankle, you are allowing some movement of the foot, and also encouraging normal (e.g. plantar) reflexes. However, please note that a fixed foot plate is required so that any leg flexion, for example, does not result in the foot plate trying to fold up.

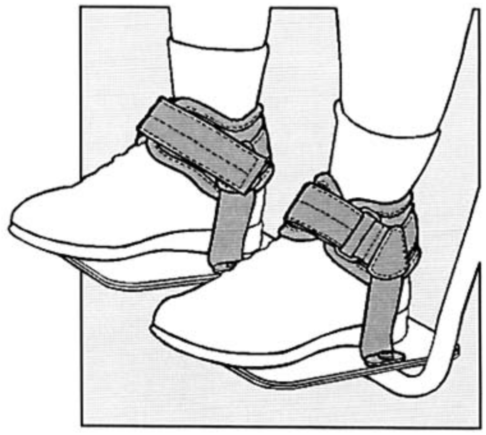


Figure 7

Do remember that the hip belt should be fastened before any foot stabilisation device is fastened down!

Stabilisation of the Trunk

Secondary supports of the trunk are placed to the anterior, and can be 'Active' or 'Passive'. A typical **active support** is a lap tray, or as it is known these days for funding reasons, an 'anterior upper extremity support system,' where the person needs to support him/herself actively. However, anything that is 'active' will produce fatigue with time, and therefore needs to be coupled with a position of rest within a system. Therefore, if the individuals do not have the pelvic control to move themselves back and forwards, they will need a dynamic tilt in space system.

With **passive supports**, these are placed on the anterior trunk surface, and are most usually shoulder harnesses of one type or another. The aim of these systems are not to clamp the body in place, but to allow and promote movement. They need to be configured so that the individual does not hang in them: the primary supports should be bearing most of the weight.

Shoulder harnesses need a firm back support, and should be fixed at the top at the same height as the top of the shoulders. Positioned lower, for example, they will only pull the individual down, figure 8. The two straps should be fixed as close as possible to each other without risk of chafing the neck. Most modern harnesses will have a tensioning device: place your hand underneath the strap while tensioning to avoid any shearing action on the person's skin underneath. Please note that most modern harnesses also have dynamic strap options which allow some movement within the harnesses while using the elasticity to pull the individual back into position.

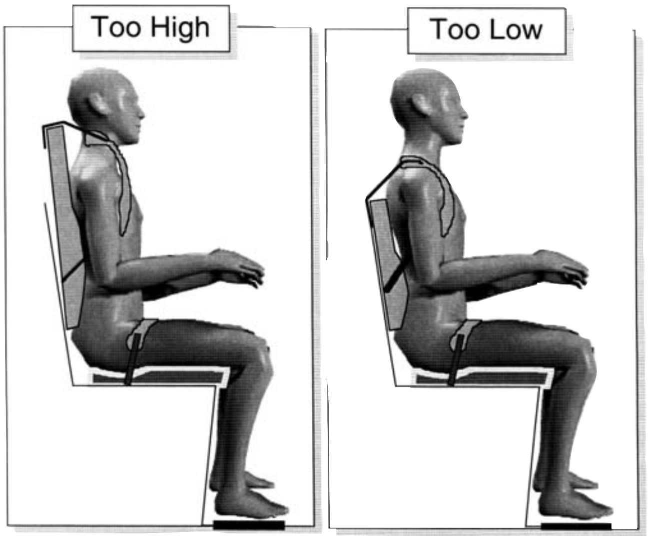


Figure 8

Configurations

Shoulder harnesses can be set up in H, X, or Backpack configurations figure 9. The H configuration provides the best compromise between support and function. However, do make sure you use a system where the

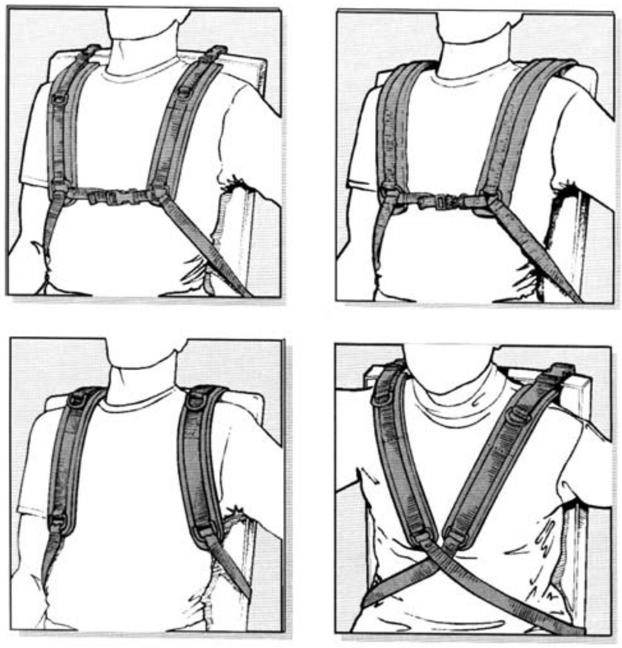


Figure 9

cross piece is placed at or below the base of the sternum: there are a number of cases reported of strangulation arising from people slipping down and having their harness catch them around the neck, especially with butterfly-type harnesses.

For the X configuration, the bottom of the pads should cross at the nipple line. Ideally the pads should be able to slide easily over each other. This configuration controls trunk extension while allowing scapular mobility and some lateral movement.

The Backpack configuration should have the lower straps fixed relatively low on the back support. This configuration promotes shoulder retraction and trunk extension, but reduces movement. However, this is useful in stabilising the head into the head support, and also can help in controlling rotation at the pelvis.

Head Stabilisation

For a head support to work, the seat needs to be set up so that the head has a tendency to fall back onto the head support. The exact placement should be where the head is falling naturally: if the head lolls laterally, then the head support should be placed somewhat laterally (and not purely posteriorally with a large lateral flap). Anterior supports are suitable where the user has no control of the head, e.g. flaccid spasticity. However, please note, if you are controlling the head to this extent it is imperative that the pelvis and trunk are supported to allow no movement of other parts of the body.

This article has tried to represent Tom Hetzel's approach as accurately as possible, but the treatments recommended may not be the most appropriate in all cases. If you would like to follow up the ideas in this article in more detail, video tapes and a course book of Tom's presentation are available from BES Rehab Ltd, 9 Cow Lane, Fulbourn, Cambridge, CB1 5HB (tel/fax 01223 882105, e-mail: b.e.s.rehab@btconnect.com

Barend ter Haar

BES Rehab Ltd (Treasurer and membership secretary PMG)

During an examination, a medical student is handed a human femur. The examiner asks the student, "How many of these do you have?" The student replies, "five." "Wrong," says the examiner, "you have two femurs."

But the student was right. How come?

First clue - page 19

PMG Annual Conference: Llandudno 2000

A Student's View: from the bursary winner

In order to gain a bursary place at this year's conference, I had to prove that I, as a third year Physiotherapy student, had an interest in wheelchairs and specialist seating. I submitted a copy of my dissertation on the subject; "The provision of wheelchairs and pressure relieving cushions for clients with Parkinson's Disease," along with a letter outlining why I felt I should get the bursary.

So, was the conference of use to me? In a word, yes! Although much of it was not directly related to either a student or a junior Physiotherapist, a lot of the information can be indirectly applied. For example, the problems of working together, as addressed by E. Parry, occur in all areas of Physiotherapy, not just within the wheelchair service. Research and development is an area that the C.S.P (Chartered Society of Physiotherapy) is trying to encourage, in line with Clinical Governance, to make Physiotherapy practice more evidence based. The talk by Dr. Lewis gave me much to consider if I decide to undertake research in the future. On a more personal note, the Audit Commission report and the York Report review supported the findings in my dissertation.

Many of the free papers discussed issues that don't and, in the short term, won't, affect me directly. However, they gave me a lot of useful information that will affect my clinical practice, particularly "The caring experience" presented by W. Murphy. "Issues of working together for Users" (A. Bruce) and "Working together" (B. Williams MP) reinforced the need for interdisciplinary teamwork, including the approach to treatment.

The interactive session and group discussion on "Barriers to an integrated service" was the section of the conference least relevant to me. However, it was interesting to note countrywide variations which were highlighted and really emphasised the need for good communication skills, both within and across services.

The conference reinforced what I already knew about the Wheelchair Service, but also gave me much to consider in terms of 24 hour posture management, wheelchair prescription, provision/funding and using a problem solving approach to achieve the best outcomes for everyone. I believe that what I learnt will directly affect my clinical practice in both the short and long term.

I feel that this is worthwhile for third year Physiotherapy students, although first and second years may not benefit as much. It has to be asked whether I would have gained as much as I did from the conference without the background knowledge I gained from personal experience. As a result of what I learnt at the conference, I have discussed subject areas, which may be better dealt with at undergraduate level with a senior member of staff at Manchester School of Physiotherapy.

Finally, I would like to thank everyone who made me feel welcome and answered my (many) questions over the 3 days, particularly; Patsy Aldersea, the Chaliey Heritage delegates, Active Design team, and Julia Cunningham.

Nicola Cunningham

Student and PMG bursary winner

Working Together

A fresh approach for disabled service users or should that be 'customers!'

This was presented by Andrew Bruce and challenged everyone reconsider what is ment by disability, imparement and independence. The following notes are taken directly from his overheads. Andrew started by outlining what he was to cover:

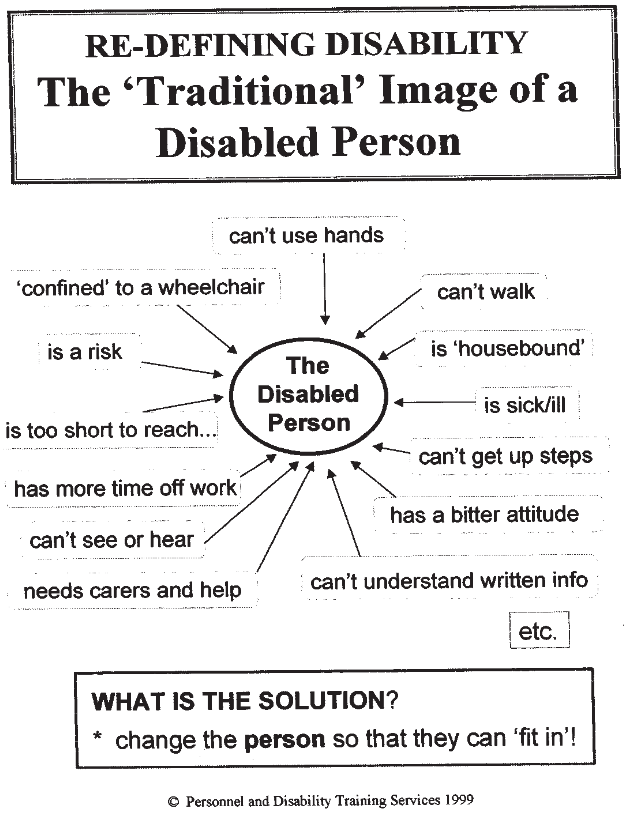
- Disabled people in the UK - key facts, and why they are important.
- What is disability? - a fresh approach.
- A Charter for disabled people using hospitals.
- An Audit Agenda - the primary areas to address.
- Working together towards independent living.

The key facts about disabled people at work, rest and play:

8m	Disabled people in the UK (in other words 14% of the population)
6.2m	Disabled people of working age, i.e. 18% of the working population - 3.3m men and 2.9m women)
2.8m	Disabled people employed in 1998 (i.e. 45% employment rate c.f. 80% for non disabled people)
11%	Unemployment rate amongst disabled people (6% for non disabled people, i.e. twice as likely)
78%	Disabled people rely on benefits for their basic income.
7 in 10	Economically active disabled people will become disabled during their working lives (n.b. high costs of replacing staff)
2.3%	Disabled students in Higher Education in UK, out of a total of approx. 1.5 million students.
5%	Disabled people are wheelchair users!
1 in 4	Customers is disabled or has a disabled person in their immediate circle (value of UK disability market = £33 billion per annum).

Source: 1998 Labour Force Survey, plus OPCS, Touche Roche and other surveys

Andrew went on to define the traditional image of a disabled person and presented two models: Individual and Social.



RE-DEFINING DISABILITY

The 'Traditional' Image of a Disabled Person

can't use hands

'confined' to a wheelchair

can't walk

is a risk

is 'housebound'

The Disabled Person

is sick/ill

is too short to reach...

can't get up steps

has more time off work

has a bitter attitude

can't see or hear

needs carers and help

can't understand written info

etc.

WHAT IS THE SOLUTION?

* change the **person** so that they can 'fit in'!

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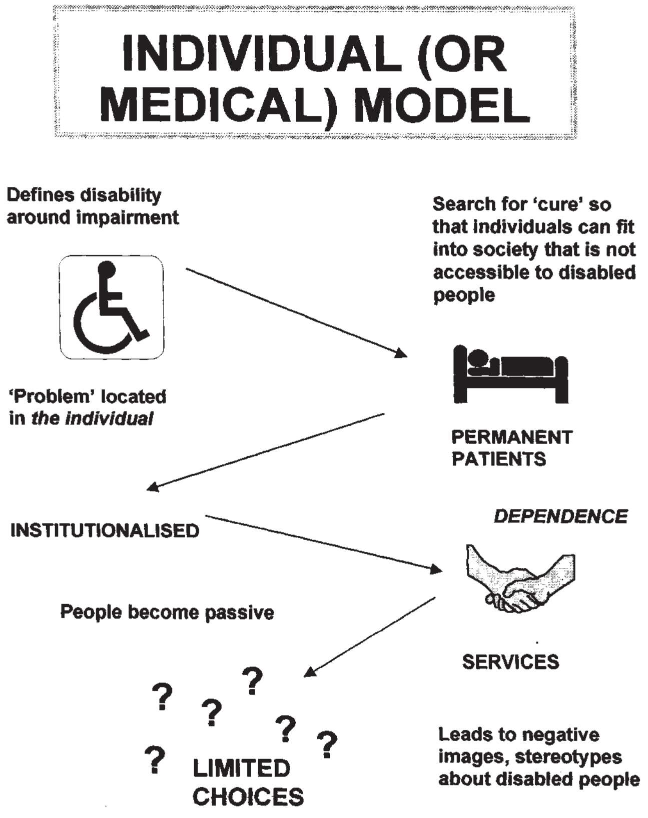


INDIVIDUAL (OR MEDICAL) MODEL

Defines disability around impairment

Search for 'cure' so that individuals can fit into society that is not accessible to disabled people

'Problem' located in *the individual*

PERMANENT PATIENTS

INSTITUTIONALISED

DEPENDENCE

People become passive

SERVICES

? ? ? ? ? ? LIMITED CHOICES

Leads to negative images, stereotypes about disabled people

THE SOCIAL MODEL

Acknowledges that:

Impairment is the functional limitation within the individual caused by a physical, mental or sensory condition

But re-defines:

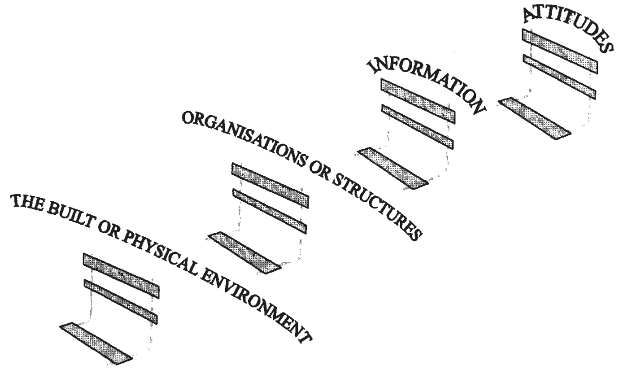
Disability as the loss or limitation of opportunity to take part equally in the mainstream of the community, as a result of physical and social barriers that do not affect others.

Benefits of adopting a social model approach result from the fact that the social model locates the `problem' outside the disabled person and therefore offers a more positive approach because:

- it doesn't `blame' the individual or turn them into the problem;
- it involves everyone in identifying solutions;
- encourages co-operative problem-solving;
- removes barriers for others as well as disabled people, that is, it is an equal opportunities model;
- acknowledges disabled people's rights to full participation as citizens.

Andrew then looked at barriers that disabled people experience before outlining the Royal College of Physicians charter for disabled people using hospitals.

THE BARRIERS WHICH DISABLED PEOPLE EXPERIENCE



RE-DEFINING DISABILITY
The Disabling World
- a fresh approach

WHAT IS THE SOLUTION?
* change **the world** to remove the barriers?

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Royal College of Physicians: A Charter For Disabled People Using Hospitals

Every disabled patient, visitor or employee has the right:

- to be treated in the same way as any other person, without pre judgement about disability or the quality of life of disabled people.
- to make use of all hospital services and facilities without avoidable hindrance.
- to relevant and accessible information, especially about the hospitals provision for disabled people.

All disabled patients have the right:

- to be asked about their personal needs in advance of a pre-arranged appointment or admission, or at the first encounter on an emergency visit or admission.
- to be consulted directly about their treatment and all arrangements made on their behalf

Every disabled patient, visitor or employee may reasonably expect:

- that all unnecessary barriers to the hospitals services are removed.
- that hospital staff recognise and respond to the needs of disabled people.
- that all aspects of the hospitals provision for disabled

people are regularly reviewed.

All disabled patients may reasonably expect:

- that the disabilities they experience are not increased by inflexible regulations or routines.

The Charter's Audit Agenda 4 main areas:

- Who has accepted responsibility?
- Communication issues.
- The Physical Environment
- Spreading awareness.

Andrew summed up with the following statements:

> **'Disability equipment services are pivotal to the success of many current initiatives to promote independent living in the community.'**
>
> *From 'Fully Equipped' Briefing of the Audit Commission*

> **'Independence means having control over your life, not doing everything for yourself. Independence is created by having assistance when and how you need it.'**
>
> *From Disability Movement.*

Andrew Bruce
F.I.P.D.

Plenary Paper Abstracts

Disability Equipment Audit Commission Report

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More than 4 million disabled people use equipment services. Equipment is the gateway to their independence, and the services that they receive have the potential to make or break the quality of their lives, and the lives of 1.7 million informal carers. It can make the difference between an enriched, independent life or a miserable, isolated existence.

The Audit Commission's report, Fully Equipped found the current standard of service to be unacceptable in many parts of the country. After enduring long waiting times, many users receive equipment and services of dubious quality. Local eligibility criteria are contain demand within available budgets. Some people are able to buy the equipment they need privately, but older or disabled people are, on average, the poorest members of society, so many have to rely on charities or go without.

Equipment services are characterised by a lack of senior management attention and clinical leadership. The current organisation of the services is a recipe for inequality and inefficiency.

Pressures are building as the population ages. Disability equipment services are pivotal to the success of many current initiatives to promote independent living in the community, so action is essential. Improvements in disability equipment services require leadership at a national level to reorganise the current fragmented arrangements and deliver more integrated services. And at a local level, senior managers need to give reviews of equipment provision a higher priority in order to deliver modern, effective services. The development of 'hub-and-spoke' arrangements and other models of integrated provision is the starting point for a better future for equipment services.

The Ups and Downs of Referrals to a National Specialist Centre
A Consideration of the Implications for Wheelchair Services

Cary Bernard
Margaret Dyke

As students on the course on Wheelchair Prescription and Provision for Professional Practice, we were required to report on an aspect of service provision. As a result of recent experiences we chose to look at the implications to Wheelchair Services of a client being referred to a national specialist centre. The outcome of such a referral can be very positive if all parties are aware of their responsibilities.

B.S.R.M. (1995) identified advantages and disadvantages of provision at District and Regional centres. Drawing on both this document and our own experience we were able to identify the advantages and disadvantages of referral to a specialist centre. It became clear that many of the disadvantages of such a referral could be ameliorated by liaison with the local Wheelchair

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Service. We looked at ways in which a positive outcome could be achieved and suggest that consideration of the following points should enable this.

- How will local therapists be contacted prior to admission and be involved in assessment?
- Who will own the equipment?
- Who will be responsible for maintenance and repair?
- Who is responsible for review of provision?
- Will prescription be made in accordance with local criteria?
- What reports will be sent to the local Wheelchair Service?

These issues should be discussed with the local commissioner to ensure that, when a referral is made to a specialist centre, the full implication for the Wheelchair Service is understood. Protocols can be devised to maximise the chances of a positive outcome and enable all parties to work towards the same aims, within the same framework.

References:

British Society of Rehabilitation (1995) Seating Needs for Complex Disabilities. A Working Party Report of the British Society of Rehabilitation Medicine. B.S.R.M., Opportunities for People with Disabilities, Royal Hospital for Neuro-disability. London. 16 Table 4.9/vii 3.6/vii 3.4.

Challenging Cases Requiring Innovative Action

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Background: The clinician is likely to encounter, fortunately rarely, cases in which the disabled person presents with problems for seating which are more than usually challenging, if not impossible, and/or with needs that are mutually exclusive. Two cases will be presented and discussed which feature multiple difficulties and conflicting requirements. The more usual approaches were not possible and required much discussion and innovation.

MN is an intelligent young woman with high spinal lesion from birth injury. MN has just finished secondary education and is now attending a college of further education. She is very outgoing and wishes to be as independent as possible The issues involved were:

- Hypersensitivity and pain in the lower legs and feet complicated transfers by hoist - A reclined position is necessary to enable intermittent catheterisation via the lower right abdomen.
- Severe and increasing scoliosis with impingement of the thorax on the pelvis; dislocated right hip joint;.
- Positioning of MN in relation to the joystick control for her powered wheelchair is critical.

FJ is a young man with cerebral palsy and learning difficulties. He has been in residential care for a number of years. At differing times in the past he has had a variety of surgical interventions for dislocation of the hip joints and contractures of the lower limbs.

FJ was able to use a joystick control and has sufficient cognitive ability to drive a powered wheelchair. Currently the severely restricted range of movement and pain at the hip joints prevents normal posture alignment in sitting. FJ spends most of his time in lying.

Aims: To achieve the degree of posture support and independent mobility required in each case. MN wished to be able to sit in her wheelchair all day, currently not possible due to discomfort and bladder management. To find an alternative to supine lying and some degree of independent mobility for FJ.

Method: Following comprehensive assessment the problems and possibilities were discussed in a combined disciplinary meeting which included the moving and handling advisor. A plan of action was devised in both cases. In MN's case a period of admission was considered necessary to address the different but complementary issues. A variety of posture support were tried and recommendations made. FJ was treated on an outreach basis as there were difficulties in transport. In addition it was felt that he would feel anxious if away from his home surroundings.

Results: In MN's case the problem of transfers was resolved. The customised seating was made and incorporated into the wheelchair using a novel interface which allowed independent changes of recline and repositioning and catheterisation.

In FJ's case support in the erect posture was achieved with some difficulty and interfaced with a customised powered base. This has enabled FJ some freedom of movement for periods of approximately two hours per day.

Conclusions: The implications for intervention in similar cases are discussed. These relate to the value of early intervention; discussion of previous interventions including surgery; the necessity of a combined approach; resources; and the fundamental need for co-operation between the disabled person, carers and professionals.

Wheelchair Provision For Clients With Motor Neurone Disease

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Background: Clients with Motor Neurone Disease (MND) are referred to MMC from a wide geographical area numbering, on average. seven clients a month in 1999. Many of these clients presented with profound generalised weakness. The provision of appropriate wheelchairs for these clients is often challenging and variable.

In our holistic assessment, postural needs are identified and recommendations of appropriate wheelchairs and postural support made to local Wheelchair Services. In our experience it is difficult for local Wheelchair Services to meet the specific postural needs of these clients with the standard wheelchairs which they have at their disposal. Standard wheelchairs do not offer adequate postural support, the need for which becomes more critical as the disease progresses.

If the Wheelchair Service is able to provide the appropriate wheelchair- from their limited budget, the delivery time is sometimes so long that it becomes inappropriate or is too late.

If the posture of the person with MND is not supported in a stable position problems occur which include: reduced function, discomfort; risk of pressure sores, adaptation of tissues leading to contractures of soft tissue.

In particular, head control is a problem for people with MND due to weak neck muscles. Sitting in a tilted position with a fully adjustable head rest is an effective way of enabling the person to support their head in a functional position.

Aims: To raise awareness of the particular postural needs of clients with MND who require wheelchairs.

Method: A retrospective review of M.N.D. clients assessed at M.M.C in I999 by identifying:

- how many were issued equipment, as recommended by the Specialist Disability Service
- other suitable equipment provided
- length of time taken to supply the equipment
- who funded the equipment

Conclusion: Clients resort to using static seating with a tilt in space facility to provide them with the postural support they require rather than using a wheelchair thus losing mobility.

Investigation into quality of information on referral forms received by Manchester and Oxford Wheelchair Services.

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Introduction: Many wheelchair services make decisions on wheelchair issue based on the information received on a referral or prescription form. The number of referrals received with insufficient information is currently as high as 30% in some services [White 1994]. This leads to delays and in some cases incorrect issue of a wheelchair. The main aim of this investigation is to improve the accuracy of wheelchairs issued based on information received on the referral form. In order to investigate this problem referrals completed by therapists are compared with those completed by GP's in both Oxfordshire and Manchester Wheelchair Services.

Procedure: A common difficulty experienced by both Oxfordshire and Manchester Wheelchair Services is incorrect issue of wheelchairs based on information given on referral forms. Currently 80% of the total number of wheelchairs are issued without an assessment by the wheelchair service, so both services rely heavily on the accuracy of information received. This results in the issue of a high percentage of inappropriate wheelchairs and many requests for exchanges and assessment. In order to improve the quality of the service provision, it was necessary to attempt to quantify the situation to investigate the scale of the problem.

In order to compare the amount of information given on the referral forms the quantity of basic information received on the referral was analysed. A sample of 50 referrals from therapists were compared with 50 from GP's in both services. Several categories of referral information were chosen as essential to accurate wheelchair prescription. The amount of information completed by each group was tabulated as a percentage and the results charted as histograms.

Conclusions: From the figures it is clear to see that therapists provide more information on referral forms than GP's. In both Manchester and Oxfordshire this applied to all categories but especially equipment recommendations and measurements, where the difference was dramatic with 95% of therapists and only 12% of GP's supplying information. This can be graphically illustrated using histogram charts [see chart]. On average therapists offer twice as much information as GP's, but from both groups there are still gaps in information which results in many referrals needing further investigation by the wheelchair service.

There are also obvious differences between the levels of information received by Manchester and Oxfordshire wheelchair services. Oxfordshire receives more information from therapists on environment, transport and attendant details. This could be due to the style of the referral form, as the Oxfordshire form appears more user friendly and asks more specific questions for example on use of chair, indoor/outdoor, daily/occasional. But Oxfordshire GP's completed fewer satisfactory referrals than Manchester, and when consulted OWS found that due to time constrictions and lack of access to information GP's are more likely to complete a concise form. Oxfordshire have now designed a separate referral form for GP's which is short and covers basic medical information only and Manchester are looking at also adopting this form along with a more user friendly prescription form for accredited therapists.

NHS FUNDING FOR R&D IN DISABILITY AND Rehabilitation

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The Culyer Report (1994) was implemented by reforming the process for making NHS funds available for support of R&D in the NHS. By gathering together in one national fund (the R&D Levy) the total amount that each Trust estimated it spent in supporting R&D, this created a framework in which it should be possible to ensure that R&D of value to the planning and evaluation of services for all patients is adequately supported. In this presentation, the various sources of R&D support will be described, together with the process by which researchers should be able to ensure that their trusts provide the necessary support and facilities.

Typically, research addressing topics collectively covered by the term "disability" have not been well-supported, and the new funding system should encourage a better balance between cutting edge biomedical research, including molecular biology and drug trials, and "lower-tech" studies directed towards the innovation or evaluation of practical interventions for large numbers of disabled people.

The key to accessing funds is to adopt a strategic, planned and incremental approach. R&D Directors are required to ensure that the R&D Levy allocated to their Trust is principally used in support of grant funded "partnership" projects, though they also have discretion to support well planned and strategically relevant studies that do not have grant support ("own-account" projects). The presentation will suggest that researchers in less fashionable areas of NHS R&D should ensure that projects are well-designed, with multidisciplinary involvement, and whenever possible should attempt to secure grant support from either Government or charitable funds. Building on small-scale pilot work to demonstrate the feasibility of the approach, it is possible to secure funding from external sponsors.

A continuing weakness of the present funding model is that in most Trusts it is difficult for the R&D management to release R&D Levy money for investment in new research areas. Therefore it would be unrealistic to suggest that even the most equitable and evidence-based process of allocation within Trusts can easily make available resources to allow either appointment of new staff or "protection" of research sessions.

Tackling Problems Of Working Together

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There are potentially many different people involved in the provision of wheelchairs and seating. These include but are not limited to: the wheelchair therapist (usually an occupational therapist or physiotherapist), the wheelchair co-ordinator/clerical assistant (either clerical or therapy helper), rehabilitation engineer or rehabilitation technologist, clinical engineer/bioengineer, contracted repairer, parents, carers, teacher, school or community therapist(s), and specialist teams. These specialist teams can include the consultant in rehabilitation medicine, senior therapist(s) (OT or PT), rehabilitation/clinical or bioengineer, orthotist, orthopaedic consultant, tissue viability nurse, dietician, to name a few (Ham, Aldersea & Porter,1998). Of course, the most important member of this team is the disabled person.

There are currently trends towards evidence based practice, clinical governance, and client centred practice. Team work has for some time been recognised as important in the process of assessment of needs. These terms will be defined and their relevance to today's changing environment will be explored.

There are significant challenges to team work. Too many people in a team can be inefficient, intimidating to the client and their family, and can be counterproductive due to a potential lack of focus. Conversely, synergistic teams can achieve more as a unit than could otherwise be achieved (the whole is greater than the sum of the parts). Such teams only accept high standards of excellence, and have strong and principled leadership that aims to unleash the talents of the team members. Interdisciplinary or multidisciplinary teams are inherently expensive in terms of manpower. A framework to achieve communication whilst using manpower efficiently will be postulated.

Drawing together different statutory, charitable, and private organisations to benefit the client can be a difficult task. The process of problem solving to enhance opportunities of working together will be explored, illustrated with case studies. The importance of recognising the unique contribution of each member of the potential team will be explored. Issues surrounding the different knowledge bases of team members will be explored, and potential solutions discussed.

References:

Ham R, Aldersea P, Porter D. (1998). *Wheelchair Users and Postural Seating- A Clinical Approach.* Churchill Livingstone; New York.

Electronic Assistive Technology Integrating Service Delivery

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It is five years since responsibility for the provision of environmental control systems was devolved from the Department of Health to Health Authorities.

In North West England with a population of 6.6 million people, services have been co-ordinated by a single provider, EAT (NW), from the Walton Centre for Neurology and Neurosurgery.

With some 700 users, spread across 16 Health Authorities, EAT(NW) has become increasingly aware of the importance of co-ordinating service delivery and of ensuring its relevance to user need. It now employs three full time electronic engineering technicians and additional to its core activity of providing and supporting environmental control systems, it is involved with the supply of simple switching systems, communication aids and computer access technology.

The presentation details the evolution of EAT (NW) and discusses alternative patterns of service delivery.

It concludes with proposals for regionally based provision with enhanced support and opportunity for therapists and technical personnel leading to the development of integrated and co-ordinated services for people with disabilities.

Evaluation of the Powered Wheelchair and Voucher Scheme Initiatives

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York Health Economics Consortium undertook an evaluation of the Powered Wheelchair and Voucher Scheme initiatives for the Department of Health during 1999[1]. Activity and cost data were collected from a variety of sources (e.g. Wheelchair Service Managers and Health Authorities), and feedback on the initiatives was obtained from service managers, physiotherapist, occupational therapists, rehabilitation engineers, and - of course - from wheelchair users. Questionnaires were sent to all of these stakeholders, with separate questionnaires for EPIOCS users, voucher users and "generic" users of wheelchair services.

The first part of the presentation will focus on some of the cost and activity data, which indicate the scope of the two initiatives and their relative costs and coverage. These data show that EPIOCs were introduced much more quickly than vouchers, and that the set-up costs associated with vouchers were comparatively high (although the allocated monies did enable many services to become computerised). The data also show considerable variations per capita in the core funding allocated to wheelchair services by Health Authorities.

The second part will consider the main messages to be drawn from the feedback from the various stakeholders. The emphasis will be on providing information of particular relevance and interest to those professionals working directly with wheelchair users on a day-to-day basis. The EPIOC scheme received almost universal support from the professionals (although there were some strong objectors, and many respondents thought that the scheme should be extended to include people with some indoor mobility but poor outdoor mobility). Despite some initial reservations, the partnership voucher scheme was generally popular once established, although some reservations remained about the independent voucher scheme. The users questionnaires revealed that although most service users were satisfied with their wheelchair, some (especially younger users) were very critical. Although most EPIOC users felt that their chair had improved their quality of life considerably, many complained that their chairs were unreliable and of poor quality.

The presentation will conclude by summarising the main conclusions from the report, and by exploring how these may be taken forward locally by service professionals.

[1] *Copies of the report can be downloaded from the Department of Health web site* - see www.doh.gov.uk/new.htm (29/3/00).

Free Paper Abstracts: Clinical

THE DILEMMA AND THE ART OF COMPROMISE

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Background: A stable posture is the basis of functional efficiency. In clinical practice a situation often arises in which the posture adopted by the disabled person in order to function leads to the development of secondary complications: contracture, deformity, discomfort and tissue damage. Intervention designed to support the posture interferes with functional performance. What can the clinician do to resolve the frequently conflicting needs of posture and function? The answer lies in compromise. The question then arises as to what constitutes the best compromise.

This problem presents most frequently in people who have gradually adapted to a progressive pathology such as in Multiple Sclerosis, Freidrich's Ataxia and Muscular Dystrophy.

Objectives:

- To determine the essentials of posture and functional requirements in a given case and to identify the priorities in order to arrive at the best compromise in the circumstances.
- To explain and justify the inevitable 'trade-offs'.
- To introduce complementary therapeutic procedures, where appropriate, for the purpose of ameliorating remaining problems.

Method: The problems and difficulties encountered in two cases where a serious conflict exists between posture and functional requirements were analysed:

- A lady with multiple sclerosis, living independently and still working, referred for reasons of discomfort and increasing scoliosis.
- A teenager, in mainstream school, with Freidrich's Ataxia, referred for reasons of discomfort and increasing scoliosis.

Each case presented with differing functional requirements and priorities The posture needs were similar but they were addressed in different ways according to the needs and wishes of the disabled person. A combined professional approach offered the most likely possibility of achieving the best compromise.

Results: Complementary procedures were introduced in one case. In both cases function took precedence over posture alignment.

Conclusions: Compromise is necessary in virtually all cases requiring external support of posture and position. Functional performance takes priority over posture considerations. While general rules can be applied, each case must be considered separately as influencing circumstances vary.

A satisfactory compromise is not always possible. Where problems remain, alternative/complementary procedures are necessary to alleviate remaining problems. An in-depth knowledge of compensatory posture strategies is requisite for all clinicians involved.

The student was healthy and was not physically abnormal. Second clue page 24

Powered Mobility for the young child.

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Introduction: An increasing number or requests are being received by Whizz-Kidz to fund powered mobility in young children.

This is the direct result of:

- Increased awareness/expectations of parents.
- Increased availability/product range.
- Increased survival of young children.
- Increased acceptance within society of disability.
- Increased integration into mainstream schools leading to different demands.

With the severe limitations on budgets in the Health Service, the needs of these children are rarely met by the Wheelchair Services.

Case Presentations: Two cases will be presented, discussing: assessment, risk assessment, prescription and outcome of provision of powered mobility in young children.

Summary: These case studies illustrate the need for a multi-disciplinary team assessment encompassing physical, developmental and environmental aspects of the child's life.

Although research from UK is limited, some benefits of early powered mobility have been well documented in the USA, including improvements in psychosocial, sensorimotor and cognitive developmental skills, as well as increases in general activity level. At present the choice of wheelchairs available for young children is very limited. The majority of these offer special functions i.e. seat elevation, tilt in space and lowering seat to floor level and are therefore very expensive. However these functions are beneficial in allowing the child to access their environment and allow maximum integration amongst their peers in a mainstream school.

Conclusion: These two cases demonstrate successful intervention but a structured evaluation is now needed with greater numbers. Results of such evaluation will hopefully lead to increased provision of powered mobility through government funding.

My Rib Bone's Connected to My Thigh Bone???

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Clinical History: N is a 22 year old female with spina bifida (lesion in the low thoracic spine, closed at birth) with complete loss of cord activity below that lesion. She walked using bilateral KAFO's and elbow crutches to the age of 12 when she adopted wheelchair mobility. She has no cognitive deficit.

Present Condition: There is complete anaesthesia and paresis below the T10 level. The spine is hyperlordotic and effectively fixed but hip movement is full. The legs are flail and are kept in sitting in full extension although knee movement range is normal. The lower limbs rapidly discolour on dependency. Upper limb movement, sensation and power is normal; she can maintain this degree of selective movement when her trunk is externally supported in the vertical position. Skin is intact.

Her habitual posture when using her wheelchair - at least eighteen hours every day - is with her legs in full extension below the hips, resting on a stump board. The hips are fully flexed so that the anterior thorax rests on the upper-surface of her thighs. In this position she is able to use her hands effectively despite the front overhang of her extended legs. She is however 30cms. shorter in ground to crown height compared with the vertical supported position.

Intervention: N was provided with a foam in place anterior wedge to bring the trunk upright. This was followed by a complementary posterior support to stabilise her trunk in the antero-posterior plane. The benefits have improved function - eating, respiration - and cosmesis

Problems:
1. should N have a spinal brace?
2. Is there a better way of handling this problem?

Free Paper Abstracts: Working Together

The Caring Experience: A Qualitative Study of Carers of People with Complex Disability

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Background: People with neurological impairment survive in significant numbers. The effect of consequent disabilities on the quality of life of these individuals and their carers is profound. Health Care Professionals (HCP's) rely on carers to determine how, where and when their disabled clients use specialist supportive equipment that they have prescribed. HCP's are often concerned that the carers do not help those in their care to use the equipment optimally. Many HCP's suggest that training for carers in the use of equipment could improve the quality of utilisation.

Aims: A qualitative study to explore the care-giving role of family members who care for someone who has a complex, profound disability, with particular reference to their attitudes towards helping those in their care to use special equipment.

Method: Based on Grounded Theory methodology, five semi-structured interviews of carers were carried out. The length of the interviews ranged from 40 to 80 minutes. Content analysis of each of the interviews was grounded by on-going review of the literature, which led to some theoretical explanations for the results of the data analysis.

Results: Are presented in the light of previous research. It emerged that the care-giving experience represents long-term misery, where carers experience considerable emotional, physical and social stress. The burden of care and on-going responsibility of their role seriously depletes their resources in terms of time and energy. It was also apparent that the nature of the relationship that carers have with HCP's is important to them. HCP's appear to have the power either to alleviate or exacerbate carer burden.

Conclusions: It appears that carers are under too much strain to be readily able to benefit from training in the use of equipment. It is suggested that education for HCP's about the demands of the care giving role on carers might encourage them to be more empathetic in their approach, and thus more able to support the carers as needed. Finally, areas for further research are identified.

Powered wheelchairs for children: Is the UK following the clinical evidence?

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Introduction: Following the publication of the McColl report in 1986 and the 'Batteries not included' campaign initiated by the Muscular Dystrophy Group (1994), indoor/outdoor powered wheelchairs (EPIOCs) became available from the NHS wheelchair services. The eligibility criteria in many services however, penalises children as they are thought to lack the ability to be independent in a powered chair unless they are at an older age, and generally secondary school. Reviewing the literature illustrates that we may be denying developmental 'growth' in these younger children.

Literature Review: Locomotion and other motor skills develop rapidly during the first three years of life and become the primary vehicle for learning, socialisation and for the healthy growth of a sense of independence, confidence, self esteem and competence. A child's cognitive and psychosocial development is influenced by his or her ability to move about in their environment independently and limited opportunities to experience normal interactions can lead to a lack of interest and a sense of helplessness. Powered wheelchairs have been issued successfully to children in the USA to children as young as 11 months but generally to those around 24 months of age in order that they coincide with the normal and expected appearance of gross motor skills.

Training programmes and tools, the need for modifications to equipment and controls and the importance of the multidisciplinary team, have all been evaluated, documented and published, and assist the professional team in their assessment, prescription, training programmes and techniques and review processes.

Parenting magazines raise questions that are hardly being addressed by the scientific literature. For example, the suitable age, ability and skills the child should demonstrate before attempting powered mobility and also the need, concurrently for physical exercise, the importance of family/carer involvement, the individual’s environment and the transportation requirements.

Conclusion: If there is no efficient ambulation after the age of one, a developmental approach to management should substitute an alternative means of mobility for the child. A lack of finances will continue to persist and be the major barrier to issuing such equipment but it is time for the clinical teams involved with assistive technology provision to children, to work together, to look at cost-benefit analysis, follow the government’s lead and practice what is already proven by peers.

References:

Butler C, Okamata GA, McKay TM, (1983) *Powered mobility for very young disabled children.* Dev. Med. Child Neurol. 25;472-474

Magnuson S (1995) *Powered mobility for young children with physical disabilities.* Phys. & Occup. Therapy in Paediatrics 15(3)71-79.

“Togetherness is a wonderful thing .....”

Ivy McGeorge MCSP, (PT)

Wheelchair Users Service Greenwich

Background: The benefits of a comprehensive, twenty-four hour posture management programme for children are well established. Three agencies - health, education and social services - may be involved in providing posture support for parts of the day and for specific purposes. This paper describes a clinic established to overcome the problems of differing agendas and duplication of provision through collaborative working.

Initial Proposal 1994: To establish a monthly clinic, staffed by clinicians from three services involved with children, to discuss provision of 24 hour posture care. The clinic to take place in an appropriate environment and have adequate equipment for assessment purposes.

Process: Stakeholders were identified and enthusiastic clinicians recruited. The business plan identified probable cost savings leading to support from local management in the three services.

Setting: The local Child Development Centre provides a warm, comfortable and friendly environment. A wide range of equipment agreed as appropriate by the clinicians and users is stored nearby.

Personnel: Clinical staff Physiotherapist (Education), Physiotherapist (Wheelchair Service), Occupational Therapist (Social Services), Senior Occupational Therapy Technician (Health) (OTTI), Generic Therapy Assistant (Health)(GTA).

Activity: Since 1996, activity has developed to the extent that a regular, monthly all day clinic is necessary. Five appointments are available during the day. Agreement with the budget holders means that a prescription requiring new equipment leads to immediate ordering. Delivery delay for this clinic averages six weeks. All equipment is delivered direct to the home address; users and carers are instructed to await the home visit by the OTT before any use is made of the equipment. During the home visit, equipment is checked, set up, adjusted, explained and demonstrated. Parents and carers are fully informed about health and safety issues and all necessary contacts provided in writing. A follow up visit is arranged for six weeks later to check for satisfactory performance in use.

Unmet Goals: Formalise education links, and sleeping equipment.

Conclusion: This clinic has been a worthwhile development in posture management locally. If the will is present, such clinics could be set up much more widely. Costs are more than offset by the improvements in service, potential improvement in outcome and better use of resources.

Free Paper Abstracts

National Survey of Wheelchair Provision to Persons with Spinal Cord Injury

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The introduction of the voucher scheme was seen by many clinicians in the spinal units as the opportunity to change and hopefully improve wheelchair provision. However, in order to assess the effect of this change, it was necessary to establish what current provision was. It was therefore decided to carry out a nation-wide survey of wheelchair provision. Although the system for provision of wheelchairs is different in Scotland, Wales and Northern Ireland, it was decided to include all eleven spinal units in the UK. This would allow a wider assessment of different systems as well as regional differences in provision.

The survey was conducted by sending a questionnaire to all patients who fulfilled the following criteria:

- had completed their initial rehabilitation in one of the UK spinal units between 1.1.1991-1.7.1997
- was resident in the UK and a NHS patient
- needed a wheelchair at the time of discharge
- had not used a voucher

This particular timeframe was chosen to ensure that wheelchairs would have been provided after the devolution of the wheelchair services in England in 1991 and before the voucher scheme took full effect towards August of 1997.

In total 2602 questionnaires were sent out, 1043 were returned - a response rate of 42%.

The data collected has given us a baseline of information relating to the types of wheelchairs issued at the time of discharge from the spinal unit, whether the patients continue to use the same type of wheelchair, and, if not, how soon after discharge they change, the reasons why, how the chairs are funded and who tends to carry out the assessment.

Who Gets Turned Down For An EPIOC?

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This survey has been performed to inform a national working group who are producing standardised assessment guidelines for EPIOC provision.

A retrospective survey has been performed on a consecutive series of patients (n=326) seen by a regional EPIOC service over a period from February 1997 - September 1999. At the clinic, cognitive, disability, medical, perceptual and visual assessments, were given followed by a practical driving test. The practical driving assessment was usually the prime determinant of prescription.

Fifty two clients were refused chairs. Their mean age was 49 (S.D, 25, range 6-90) years. There were 28 (54%) men and 24 (46%) women. Previous EPIOC users were 10 (19%), EPIC users 20 (38%) and manual users 22 (42%). Multiple sclerosis (14) and Cerebral palsy (11) were the main diagnoses with most other conditions being neurological.

Poor chair control was the commonest reason for refusal of provision (28); with cognitive deficits (lacked concentration or memory) (18); visual loss or visual inattention (12); and neglect (8) being frequent. Other reasons included poor traffic awareness (7) and blackouts/epilepsy (2).

Following refusal, 23 (44%) were referred for an EPIC, 12 (23%) were given other advice and 4 (8%) were referred for further training.

Our refusal rate was 16% of those assessed, which included l0 who were using EPIOCs already. Failure of the driving test was the primary reason for refusal.

The Effectiveness of Postural Management Programmes in Reducing Hip Dislocation and Spinal Curvature in Children with Bilateral Cerebral Palsy

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This paper will present the findings of a retrospective review of 57 children with bilateral cerebral palsy which aims to determine associations between interventions and hip and spinal status. The medical, therapy and engineering notes and X rays of 57 children with bilateral cerebral palsy, whose ages range from 3.2 to 18.4 years at the end of the review period, were recorded and analysed. All children included on the study had been using postural management interventions for at least two years and had no other condition which would compromise their musculoskeletal development. The children were selected from students attending Chailey Heritage School, outpatients at the Chailey Heritage Clinical Services posture clinic and a group of children using the Oxfordshire wheelchair service.

Current figures for the incidence of hip dislocation in children with bilateral cerebral palsy is approximately 39% (Scrutton & Baird 1997). A large proportion of children with bilateral cerebral palsy do not achieve independent walking and in the Scrutton & Baird study 62% of the group had not walked independently by 5 years and of these 58% had a hip problem in one or both hips. The incidence of spinal curvature is approximately 5 % in children with diplegia but rises dramatically to 70% in children with quadriplegia (Bernstein & Bernstein 1990).

The focus of this paper will be outcome measures using the Chailey Levels of Ability, Hip Migration Percentage and Cobb Angles. The interventions recorded included type of postural management intervention and surgery. The postural management interventions were rationalised for statistical analysis into three categories of using the range of Chailey Adjustable Postural Supports (CAPS) in lying sitting and standing, using two items of the CAPS range or using the seat only and other approaches.

Some of the statistically significant findings from this study show that 67% of children with safe hips when starting to use the full range of CAPS equipment maintained safe hips; children with both hips subluxated or dislocated had greater levels of spinal curvature; children undergoing surgery had significantly worse outcomes than those not having surgery.

References:

Scrutton D & Baird G (1997) *Surveillance Measures of the hips of children with bilateral cerebral palsy.* Archives of Disease in Childhood 76:381-384

Bernstein S M & Bernstein L(1990) *Spinal Deformity in the patient with cerebral palsy.* Spine: State of the Art Reviews 4(1):147 -160

She had never had any kind of medical operation. Third clue page 38

Free Paper Abstracts: Technical

Wheelchair Seating: What's What and Where

Barend ter Haar

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What do you place your feet on in a wheelchair? Is it a footrest or is it a foot support? What attaches the foot support to the chair? Should it be a leg rest, as it is commonly called? Surely a leg rest should be something on which a leg rests! Is the canvas at the rear of a wheelchair a back, a back rest, or a back support?

These are some of the inconsistencies which are being addressed in the ISO standards discussions (the ISO working group's answers to the questions are respectively: foot support, hanger bracket, back support).

Another area being addressed in the area of terminology is where different angles are being measured from, in descriptions of the relative positions of parts of the anatomy to each other, the relative positions of parts of the wheelchair to each other, and the relative positions of the wheelchair occupant to the parts of the wheelchair. For example, the position and the angles that the thighs and the spine emerge from the pelvis are taken from an imaginary line between the greater trochanters. Any recline of the spine from the vertical is a positive angle. Any lean forward is a negative angle. The outcome of these proposed descriptions will remove the need for using terms such as 'forward' and 'back', 'up' or 'raised' and 'down' or 'lowered' which are relative terms, and instead there will be definitive measurements taken from the vertical and horizontal.

The aim of these international deliberations is to try to find a common set of terms from which we all understand the same meaning and from which any chance of ambiguity is removed.

This presentation will be in part a mini workshop to present the latest stage in the discussions and recommended outcomes, including updates from the most recent ISO meeting in Vancouver at the end of February. This will also be an opportunity to add your views on the process so far, so that those views can be brought to the next meeting in Stockholm in May. If you feel that the proposals are, for example, unworkable, then your input to a better proposal will be welcomed. For those proposals which you find helpful, your assistance in propagating these changes will be appreciated.

Towards an Improved Method for Measuring the Stability of Wheelchairs

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Currently, Wheelchair Services in West Midlands Region perform stability tests when supplying a Special Seating insert. The test takes the form of a static ramp test fixed at one of two angles. These angles of 12 and 16 degrees, represent a pass or fail for attendant push and self propelling/electric wheelchairs respectively. This method of testing does not provide any other factual information when considering other scenarios, i.e., it cannot determine the actual angle of stability which could be taken into account if carrying out a risk assessment. A prototype of a variable angle ramp has been made in the Rehabilitation Engineering Department, to measure angles in a similar manner to that described in ISO 7176-1. However, the information gained is still restricted to static stability and determining other factors such as the effect of wheel position, is a matter of trial and error. Furthermore, there are health and safety hazards for the wheelchair occupant and the testers, in performing either of these tests.

A project, sponsored by the West Midlands District Wheelchair Services, is currently underway to develop a system of measuring wheelchair static stability, which either eliminates or reduces the hazards to acceptable levels. It will also measure some aspects of dynamic stability. This is to be combined with a risk assessment procedure, currently being developed, to assess the risk of a wheelchair user from an adverse incident such as tipping or sliding.

Work to date has concentrated on developing a measurement system based on measuring the weight under each wheel. This work builds on the results of Anton Wawrzinek, a researcher based at the University Of Berlin. The technique being developed in Birmingham has been used at Berlin University successfully for ten years.

The method under development uses four electronic weigh scales positioned under each wheel to measure the weight distribution of the wheelchair both with the wheelchair level and at a slight angle. This information is used, together with wheelchair geometry information to calculate the angle of static stability. If the coefficient of friction for the tyres is known, then it is possible to calculate the angles at which the wheelchair would slide rather than tip. Maximum values of acceleration and deceleration without tipping or sliding can be predicted for inclines, cambers or a combination of the two. Using this method, it is possible to explore scenarios to increase wheelchair performance and/or reduce the risk of an adverse incident for a particular client. Software has been developed to exploit this feature, for example it can be used to determine an acceptable angle of static stability whilst minimising the wheelbase of a wheelchair.

Independent testing is currently underway to compare results obtained using this technique with results obtained from tests performed to I507176-1.

A Shoulder Harness Mounting Kit

lan Warner, Engineer
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For a shoulder harness to be mounted correctly, the top of the harness should be fixed so that the top straps are placed horizontally and level with the top of the shoulders. Many wheelchairs, particularly those designed to be folded, do not have a fixation point at this height and which is solid enough on which to mount a shoulder harness appropriately. Obviously, if a shoulder harness is fixed too low, then the wheelchair occupant is pulled downwards. If the harness top straps are positioned too far apart, the harness does not position properly, with the risk of it falling off the shoulders.

Stedner Ltd has designed for B.E.S. Rehab Ltd, a mounting kit which overcomes these problems. The basis of this is the StednerTM Mounting which is a mounting system that can be attached to the back uprights, including over canvas. Into this is placed the harness mounting system which offers the following benefits:

- Ease of mounting.
- Removable single-handed.
- Unobtrusive.
- Has variable adjustability for height, width and angle.
- Strength to meet ISO wheelchair standards testing.

This system will allow wheelchair occupants whose wheelchairs have even the most basic of foldable systems with canvas back supports and attendant push handles to have a firm appropriately positioned fixation point for a upper body positioning harness.

Head Restraints in Wheelchairs/Seating in Vehicles

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This study is to review the guidance for use and the test methodology for head restraints fitted to wheelchairs used in vehicles, with the intention of stimulating debate and/or amendments, additions to current draft guidance and standards.

Should the wheelchair traveller have a head restraint when so many of us travel in similar situations without one? If so, should it be fitted to the vehicle or wheelchair? How do we know the one that is fitted is safe?

The latest draft MDA/DETR (2000) guidance on this is ambiguous in its advice about use. "The possible need for a head support" and "Some accessories are not suitable for use in transport ...... head supports". This is not as unequivocal as past advice "always use a headrest".

The draft standard ISO/DIS 7176-19 (1999) does not have a specific test methodology for head restraints. The data, table 4, measures the excursion of the head in relation to the sled not the torso. Allowing 400mm of head movement of the back remains firm. Recent medical studies have shown only a small amount of movement is needed to cause injury.

Neither guidance nor standard addresses the problem of the conflict between postural correctness and practical safety in transport, when the postural head support is mounted to one side and not directly in line with the force. Nor whose responsibility it is to provide or pay for a head restraint.

Current manufacturing guidance is not always understood or acted upon resulting in two recent revisions. Even then there are no specific claims by the manufacturers concerning the role of their head restraints when used in transport.

Conclusions: There is a need for the questions posed to be resolved and if wheelchairs are to be fitted with "travel safe" head restraints, there is a need for clearer guidance and specific test methodology.

References:

MDA/DETR Draft "Guidance on safe transportation of wheelchair users seated in their wheelchairs" 2000 International standard - Draft ISO/DIS 7176-19 "Wheeled mobility devices for use in motor vehicles" 1999.

Guidelines for Selecting a Wheelchair Head Support

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Selecting a suitable wheelchair head support can be very challenging. A complex process is involved in which consideration needs to be given to the individual requirements and preferences, physical abilities/difficulties of the user (including the carer), the type of chair and the position/s in which the support will be used. People requiring head supports are often dependent on the knowledge and expertise of therapists to guide them in their selection of a head support, yet literature related to the subject is limited and many therapists have not had the opportunity to access the complete range of head supports that are available.

A user based evaluation of wheelchair head supports has been undertaken by the Southampton Disability Equipment Assessment Centre which is funded by the Medical Devices Agency an Executive Agency of the Department of Health. All head supports that were marketed as being able to fit more than one model of wheelchair were included.

Aims:

- Identification of head support needs and the extent to which they were being met.
- Identification of important factors and features of head supports.
- Context specific information about head support performance.
- To produce guidelines to assist with head support selection.

A two stage evaluation was undertaken in order to take account of the complexities involved. Stage 1, incorporated a survey of 57 users of wheelchair head supports based on semi structured interviews and assessment of posture in the wheelchair. To gain comparative information about the function of the head supports seven purposefully selected case studies were carried out to cover a range of needs and product usage. Participants were able to select and try up to three different head supports each for a one week period. Semi structured interviews were conducted following each period of product use. The interviews were taped, transcribed and analysed for content.

The survey and case studies demonstrated that head supports are used for a variety of purposes and that desirable set-up and shape/surface of the support is very much influenced by personal preference. The combined findings of this evaluation have been utilised to develop guidelines in head support selection and form the basis of this presentation. Areas to be covered are:

- Determining the purpose of the head support
- The importance of choice and overcoming the obstacles of choice
- The influence of sitting position on head stability and head movement
- Determining the optimal head position and selecting the shape and surface of the head support which are most likely to achieve this.

Illustrative situations and cases will be referred to throughout the presentation.

This study indicates that a thorough assessment and increased choice can help to identify products that more fully meet user needs.

Workshop Summary Reports

The workshops were based on the outcome of a disscussion session chaired by Dr David Thornberry. The theme was ‘working together’ and the floor were encouraged to raise topics which related to the many issues surrounding working together. The topics raised where subdivided into 5 categories, the content of which were dealt with in 5 workshops.

The following details the scope of the five categories and summary reports by the chairs of each of the workshops.

1. **Links between services: w/c service, education, social services, regional centres, ways to improve communication, e.g. appropriate IT. Chair Ros Ham.**

Issues raised by the floor

- Budgets, joined up budget, ownership of budget
- Differences in service provision and how they relate with services such as education
- Wheelchair user groups, how to set one up
- Audit commission report, issues related to
- Interface with regional services, (local and regional relationship) and centres of excellence
- Integration with users
- Who should manage wheelchair services
- Cross service provision
- Local provision of specialist services

2. **Links between other services: Community health, charities, manufactures/suppliers, transport providers. Chair Pru Cartwright.**

Issues raised by the floor

- Transportation
- Primary care groups, trusts
- Working to provide EAT (environmental controls), integrated assessment
- Cross service provision
- Relationship with manufactures, charities, w/c services
- Tissue viability, integrating with nursing homes, district nurses

3. **Clinical issues: communication between surgeons, orthotists etc. and equipment providers to co-ordinate effective posture management programs. Chair Dr Marks**

Issues raised by the floor

- Seamless service for all posture and mobility provision
- Integration within health service, different health departments, surgery and w/c services -communication
- Medical intervention working with w/c services

4. **Education and training: attitudes, staff, training of users, evidence based practice, different options, managerial views, training currently available, CPD. Chairs Roy Nelham and Donna Cowan**

Issues raised by the floor

- Strongly held views of management not supported by evidence
- education and training (users and carers) in appro-

priate use of equipment in all spheres of life - communication problems with

- Who is responsible? Handover responsibility, paperwork
- Education of professional staff, what other services provide and how to access, would joint training be helpful
- High turn over of staff in care centres - on going training for such centres
- Language barriers with users
- Poor communication with users from service providers, difficulties

5. Communication and IT. Chair Paul Richardson

Issues raised by the floor

- Record keeping
- Data bases
- IT needed
- Training needs

Links Between Services (Inner Circle)

Chair: Ros Ham

Recommended Models of Service Delivery

A.

The 2 groups agreed with the principle of the specialist centre or hub where complex cases are seen. Such centres include prosthetics, orthotics, EAT, Special seating, EC and CA. In some wheelchair services it was felt that current level of expertise is equal to that of the hub and that referral would not be necessary. This of course (as with the hubs) is dependent on staff in post and could change in either way at any time. Distances for a user to travel was an issue and satellite clinics where the centre came out were also recommended.

B.

A Borough based integrated centres where services such as wheelchairs, nursing/medical equipment loans, tissue viability, continence, social service equipment loans, walking aids and perhaps independent living centre where found under one roof was recommended. This would facilitate exchange of ideas at a local level, promote inter-agency working and assist with communication, equipment retrieval, recycling etc. A database that covered all areas and linked with GPs was also suggested as being ideal. Funding would be pooled with accredited staff allowed to access the various equipment when they were trained.

Communication

1. Always written and not verbal between professionals and users/carers. Ensure language is appropriate.
2. Use of `books' to facilitate inter-agency working. Client's responsibilities also discussed. (Rights one way, responsibilities the other).
3. Training of staff across all service areas, users, carers, and nursing homes. Organise training sessions at base or at the staff hub on a regular basis to maximise the use of staff time. Managers must be made to understand the importance of the training and get all the staff to attend over a certain period. CPD type programme for nurse's carer's etc. They also need to take responsibility for passing on the training to their staff
4. Users responsibilities versus rights. I.e. return equipment!
5. Appointments may DNA. Look at different ways of making them and raising the importance of the appointments and the costs of DNA's and the time for a new appointment. Do users know the rep only comes every 2 months? ? Penalties.
6. Protocols for practice need to be drawn up locally and discussed with stakeholders before being implemented. They need to be widely known between the services so each member of staff knows what is happening and available. Standards need to be agreed throughout the country and **PMG could have a role here**. Standards should not go to the lowest but as a consensus of what is regarded as the minimum best practice.
7. User groups. Some have success some not. Group needs to have the support of the manager and expenses need to be paid to attendees? Could PMG review guidelines and centres where there are good groups, these could be highlighted on the web maybe, and ideas shared?. Only 50% have them, how do they know they are doing what the local users want from their service? (Audit commission).
8. Personalities/people make things happen. They are proactive, motivated, see need and do not stand back. They work towards making things better for the users. Put yourself in their shoes. What would you want if it were you?

Every human is born with two femurs.
Answer page 38

Links between other Services & Agencies

Chair: Pru Cartwright

Six areas were discussed:

- Transportation
- Primary Care Groups/Trusts (P.C.G./T.s)
- Environmental Assistive Technology (E.A.T.)
- Manufacturers and Retailers
- Charities
- Tissue Viability Services

The following themes emerged

1. Communication

The keystone to closer working:

- Each service/agency must be responsible for ensuring relevant information is disseminated appropriately and feedback given
- Client held notes helpful in some cases
- Keyworker systems can aid communications

2. Team working

Not always as easy as it sounds. Essential points:

- Selection of appropriate members
- Selection of team leader
- Ensuring inclusiveness, not excluding important players

Team working can be at committee level or simply carrying out joint assessments.

3. Joint Training

One of the best ways to enhance links across services and agencies. There are good examples of this already happening, i.e. Wheelchair Services, joint loan stores, manufacturers and tissue viability all run cross service courses, but they are sporadic and need developing to be more inclusive, especially with charities, retailers and transport agencies.

4. Taking Responsibility

Responsibility for all the above issues is also joint and that includes the users and carers.

5. Guidelines and Regulations

These are essential in developing understanding, joint working and equality of service. More needs to be done, but the P. & M.G. guidelines and the Transport Guidelines (about to be published) are good examples. Monitoring systems must also be developed.

Points to remember:

- Work towards Best Practice using Evidence Based Practice, where possible.
- E.A.T - need to identify relevant agencies.
- Be aware of the new Transport guidelines from M.D.A.
- The immediate problem over charging from geographically based Wheelchair Services to P.C.G. lists needs resolving - can the P. & M.G. help?
- Tissue viability specialists not being used enough.

Clinical Issues

Chair: Dr Marks

i.e. Communication between Surgeons, Orthotists, etc. and Equipment Providers, to co-ordinate effective postural management programmes - seamless service provision.

Methodology

The Workshops addressed this issue in 3 ways:

1. They first looked at the number of different personnel within an acute health system, identified various groupings within these personnel and worked out the various linkages between them.
2. They identified the range of equipment provided (children were predominantly the model) and linked these back to the providing agencies.
3. The groups considered barriers to working across the various agencies and interfaces identified.

Outcomes

The result of the discussions can be grouped under 3 main headings:

a) Improving communication

Both Workshops were in no doubt that improved information technology should improve communication. However, it was also agreed that many units at present did not have access to appropriate IT and this may be some time away.

Alternative strategies were therefore considered. Information was much better written than verbal and obviously letters and discharge summaries should be circulated as far as possible to all concerned. However, we finally agreed on the concept of a client centred diary. This would track critical dates, provide names and contact numbers of current professionals, and allow brief details of equipment or procedures. The advantages of it remaining brief would mean that it avoids a lot of technical jargon and doesn't get too voluminous. However, it will not replace professionals contacting each other for more specific detailed information.

The groups acknowledged that diaries could be lost and it was likely that the most vulnerable groups would be the ones who failed to bring the diary to appointments. It was therefore felt that a **key co-ordinator** nominated by the patient or their family was also important. This could be any member of the multi-disciplinary team, or might be the mother or an advocate, but ideally they should be somebody who is likely to be in long-term contact with the user.

Finally, we got a bit futuristic and talked about information technology providing people with personalised swipe cards, or the possibility of implanted chips, containing updated health information.

b) "Avoiding the panic situation"
We agreed that it was difficult to avoid all emergencies but it was quite important for wheelchair services to be pro-active in networking. This means advertising your services and getting to know the surgeons and orthotists in your particular area.

Another way of highlighting the equipment provision in an episode of care would be to get the requirement for equipment written into integrated care pathways, for example, with hip or spinal surgery.

It is clear that various agencies provide equipment for temporary use. Sometimes this is local Wheelchair Services, sometimes it is Social Services, and sometimes it is joint provision. What is most important is that someone is available to provide equipment short-term and quickly. Most specifically, the equipment must be readily adaptable, both in size and usage, and it must always be made quite clear that it is an interim provision until a more formal assessment and provision can be organised.

c) Working towards seamless provision
The Workshops considered the use of certification as a useful tool. However, it was only felt that this documents a basic knowledge base and doesn't represent experience or personality. It will never replace the "clinical trust" that comes from working with people and getting to know them.

There was a lot of discussion about the issue of separating assessments and funding. This varied from needs led assessments, possibly by joint agencies with divorced central funding, to giving individuals money for equipment, perhaps along the lines of increasing Disability Living Allowance. Neither of these extremes were found to be palatable and it was accepted that some kind of financial responsibility should be attached to the assessment.

The most useful outcome of this part of the Workshop was agreement towards timely joint assessments, for example, with children at the start of primary school or as they are going into upper school, or indeed, as they are leaving school, with handover transition to adult services. If one was looking at an adult it might be moving from slow stream rehabilitation into a full time community unit, or from residential care, into a community unit for example.

We had asked the PMG to consider a trial of the diary system. However, Christine Turner in the subsequent discussion, indicated that BHTA are already investigating a limited trial along these lines. Can we keep this in view please.

Education, Training and Attitudes

Chairs: Roy Nelham, Donna Cowan

These two workshops each had a different leader and a different outcome was achieved and is reported below.

First Group

This group chose to look at the subject in 3 specific aspects namely

1. Education and training of users and carers
2. Education and training of providers
3. Strongly held views and evidence based practice

1. Education and training of users and carers

- The users and carers include the family and any employed carers and the clients themselves
- Clients often disempowered by services and clients skills not used
- There is generally a low self esteem within family and carers leading to disempowerment and lack of

confidence

- Frequently the client/family/carers have the wrong expectations of services/equipment compared with the actual purpose and outcome of the assessment/prescription processes. There is an urgent need to ensure through communication that such confusion is minimised.
- There is a frequent turnover of care staff which exacerbates training and education needs.
- Carers are often undervalued and may not have access to appropriate training for their care role.
- The handover of equipment requires clear documentation and instructions with reference points and contact names/telephone numbers.
- All communication/instructions/handover processes/follow-up (in fact all processes) need to be in the clients' and carers' own language to ensure consistency and understanding.
- Education and training of clients not seen as part of a clinical role with the risk that it will be abandoned/neglected. Need for charging/income generation is likely to preclude most clients/families/carers from receiving appropriate quality training.

2. Education and training of providers.

- Frequent staff turnover lead to frequent and ongoing need of education and training with resource implications.
- The time tabling of training is also important within this context.
- Training of providers by other providers is not always seen as part of the funded clinical role which leads to further resource implications and income generating needs.
- The volume of training required is unknown and thereby difficult to address.
- How do the providers/clients know that what is being delivered is best practice?

3. Strongly held views and evidence based practice.

The group expressed concern which would indicate that strongly held views are often overriding evidence based practice in the delivery of services.

- **Managers with insufficient or out of date knowledge are leading services.**
- **Clinical views are often ignored in the face of budget constraints.**
- **Budget led criteria led to unmet need.**
- **Unmet need not on a list or documented because it is outside the budget led criteria.**
- **Uninformed cost improvements/budget cuts further harm clinical effectiveness whilst meeting financial need.**

The group having explored the above issues and problems then proposed some thoughts and ideas for a way forward.

Way ahead

- Use the client's knowledge, skills and power to enhance/promote effective service delivery.
- Involve client/carer/family and respect their knowledge skills and understanding.
- Empower the client/family/carer to manage own requirements and seek assistance and help when required.
- Clear procedures and documentation are required. All instructions/communications/documentation for the client/family/carers to be written in their language and check it is understood. Increase the awareness, recognition and value of properly managed care plans.
- Document unmet need falling outside of any criteria.
- Use "best value" processes to support evidence based practice.
- Establish "joined up" clinical pathways via communication and empowered clients/families/carers.
- Use PMG (and website) to collect, filter and disseminate best practice to inform clinical reasoning of service providers and assist understanding and empowerment of clients.
- Use the recent Audit Commission report "Fully Equipped" as a positive resource identifying shortfalls as a means to effecting change from a clinical/service provision/client focused perspective.

Second Group

Issues associated with ET & A

Staff retention

- Better training lead to better job satisfaction.
- There needs to be an emphasis in professional job descriptions on training and education.
- Resources for training required - currently there is inequity.

How to get around problems associated with joined up working w.r.t ET&A

Services should provide training/education to other services/agencies such as:

GP, consultants, OT, PT SLT, SNCOs (in Health, Social Service and Education)

Information shared should be:

- Service structure
- Procedures
- Remit
- Eligibility criteria
- Need to work as teams
- Resource limitations
- Information required by service from others
- Access to service

Some of these can only be gained locally once in a service but many could be taught at degree/diploma level to engender a concept of working as part of a team larger than just a single service or agency. This would provide better understanding of other services/agencies.

- There is a need to look at training and education of professionals in the Rehab field globally especially where joined up working is more common.
- There is a need for proper support structure post qualification
- There is a need for more than guidelines on what courses should contain to ensure all courses include elements of education about other agencies/services
- Possibly managers could liaise and feedback nationally on what training is required
- Core course for rehab professionals are a good idea e.g. RESNA however resources should be available to do such courses

Training carers

Training carers in the use of equipment is time consuming and costly particularly if the carers change regularly. Input is required several times to ensure understanding.

- Possibly voluntary agencies could take up some of this training in particular basic equipment awareness and issues.
- NVQ for professional cares would ensure a number of basic areas were addressed including awareness of equipment and its importance

Communications, Records and IT

Paul Richardson,
Julia Cunningham and Geoff Bardsley

Communication was so crucial to each of the categories that it required a workshop unto itself.

Communications and Records

- We would like a common format for Wheelchair Service Databases.
- Could be achieved by agreed specification.
- May be a case for separating Clinical/Equipment aspects.
- Must track all parts and accessories.
- Believe this could only be achieved if devolved from the "top"
- Would like to see the PMG lobby for this.

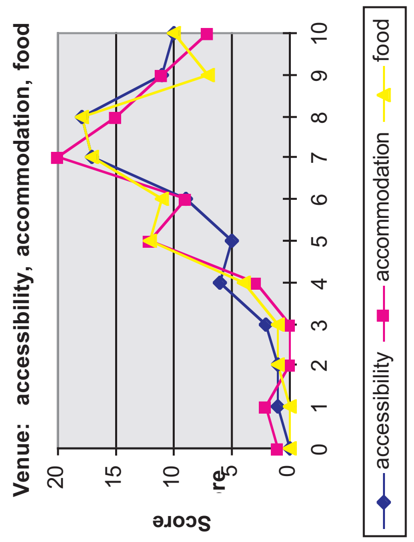
Communications and IT

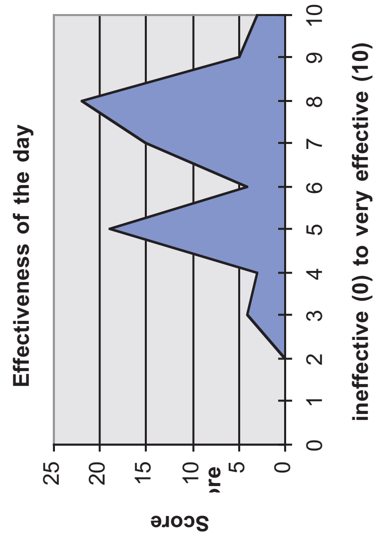
- Resourcing of IT is better but still has some way to go.
- Agreement that significant information can now be distributed by CD.
- Email now more common - but beware popularity!
- You still have to do the hard yards!

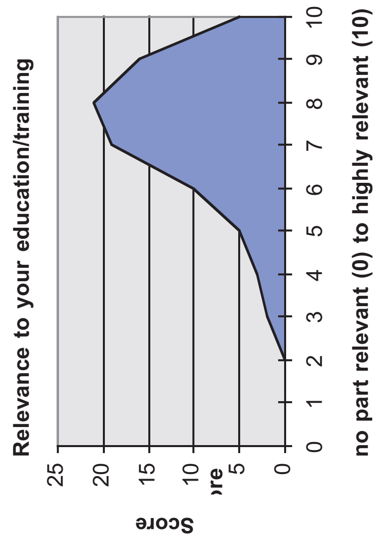
Multi-Agency Communication

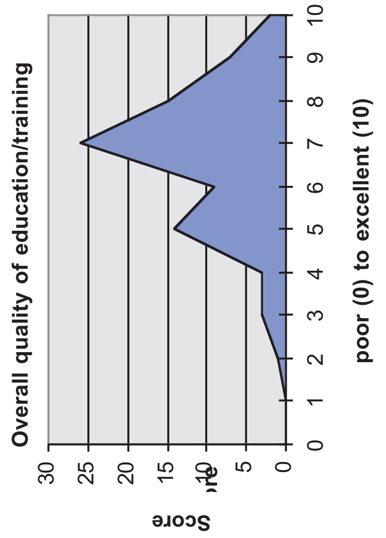
- Talk before you require the collaboration.
- Set up protocols - as detailed as necessary.
- Services on same site make it easier.
- Personal initiative has been responsible for success thus far.
- Ensure you speak the same LANGUAGE.
- Joint education exercise is powerful tool.
- Avoid multi-stage approval processes.

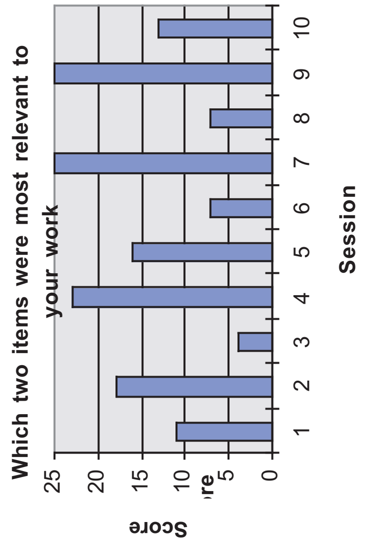
Meeting Evaluation for the PMG National Conference: Llandudno 10th-12th April 2000

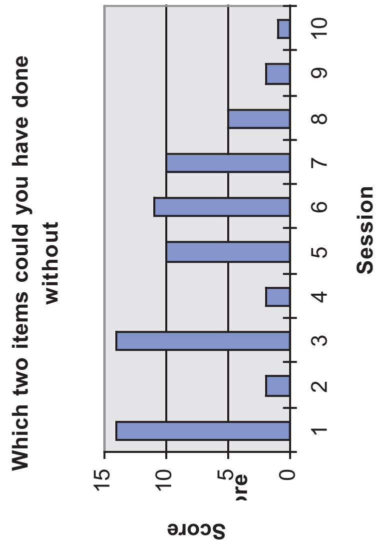


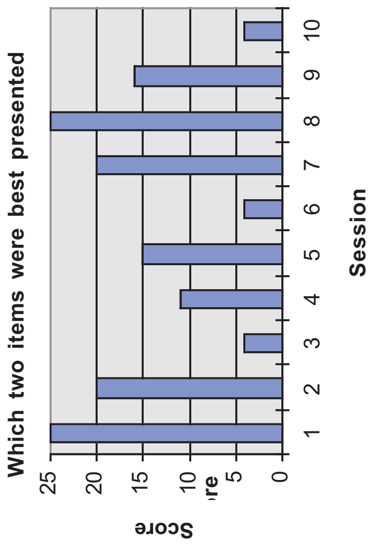


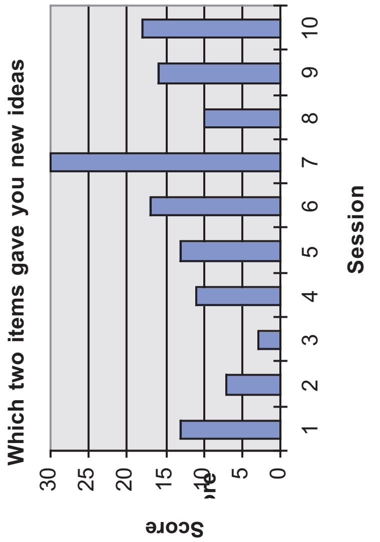


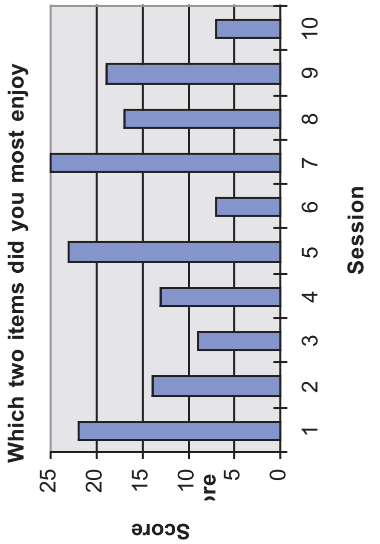












Annual General Meeting at Llandudno 2000
12:00 Tuesday 11th April 2000

00 AGM.1 Membership

More than 30 members present.

00 AGM.2 Apologies for Absence

Robin Luff, Margaret Hayes and Henry Lumley.

00 AGM.3 Minutes of previous meeting

Proposed Patsy Aldersea, Seconded Archie Goldmead, agreed *nem con.*

00 AGM.4 Matters arising

None.

00 AGM.5 Chairman's report

See page **

Questions: Tony Fielding asked who represents the membership on the Standards Committee. The Chairman responded that he represented PMG and that Geoff Bardsley, Ray Hodginson and Barend ter Haar were also on the committee.

00 AGM.6 Treasurer’s and membership Report

Barend ter Haar reported that the membership had doubled in 2 yrs. He went on to clarify points on the distributed statement of accounts.

Questions: Ros Ham congratulated the PMG on the amount of work done and the amount of money that has been raised. Roy Nelham replied that the PMG is not here to make money but a reasonable balance is needed to assure successful conferences and to allow such ventures as book subsidies.

Geoff Bardsley asked about the amount of money available, could this be used for training projects, bursaries etc? Roy Nelham replied that use of funds for further educational projects are being looked at.

Barend ter Haar stated that total running costs for a conference are around £60,000 so at least £30,000 is needed available in the account. Accounts accepted as a true record. Proposed by Hugh Crawford, seconded by Linda Marks.

Copies of the Treasurers report are available from Barend ter Haar tel. 01223 882105.

00 AGM.7 Secretarial support

A secretary is now provided to take minutes at committee meetings for a trial period so that the PMG secretary can participate more fully in meetings.

00 AGM.8

The Chairman drew the meetings attention to Barend ter Haar’s role at the conference as conference organiser adn thanked him for all his work.

00 AGM.9 Elections to committee

David Thornberry is standing down - he was thanked for all his work including his time as Chairman by Roy Nelham.

Four nominations were received and a total of 161 votes. The results were as follows:

Emma Parry	44 votes
Simon Fielden	43 votes
Gordon McQuilton	42 votes
Henry Lumley	32 votes

Emma Parry and Simon Fielden are therefore voted onto the committee.

00 AGM.10 Future conference venues

2001 Nottingham Jubilee campus 2nd and 3rd April.

Barend ter Haar said that there are problems finding suitable venues and if anyone has knowledge of a good site, the committee would be delighted to hear from them.

From the floor it was felt that a 3 day conference is too long and could future conferences be restricted to 2 days.

00 AGM.11 Any Other Business

None. Meeting closed.

POSTURE AND MOBILITY GROUP FOR ENGLAND AND WALES CHAIRMAN'S REPORT TO THE ANNUAL GENERAL MEETING APRIL 11th 2000 THE LLANDUDNO CONFERENCE CENTRE

Introduction

First, I would like to pay tribute to our previous Chairman Robin Luff, who provided solid leadership to the committee and served the membership well. He steered the PMG as we gained an increasing national profile and the attendance at our conferences paid tribute to the importance of the event. Behind the scenes his "inside" knowledge never ceased to amaze me and served to guide us in maintaining the relevance of our activities. Thank you Robin. You are a hard act to follow.

This year, my first as your Chairman, has a been a very busy one for the committee as we planned for this somewhat different meeting at Llandudno. Even though we are experimenting with a half day start and finish and the conference stretches to a total of three days (very difficult for many of our members). I am impressed with the large number of registrations which, as I write, are expected to exceed 300. I am proud to be the chairman of the PMG, an organisation that can depend on such a strength of support, and I will ensure that we continue to represent the views, aims and objectives of our members. As I wrote in the last Newsletter, the committee can only do this if we know what you want of your organisation....... which brings me to this particular conference.

Llandudno Conference

We had a gratifying number of abstracts submitted for this meeting and for the first time had to reject quite a few. Thank you to everyone involved for your support and desire to be included in the presentations at this conference. Selection was not an easy task and we have included some of the submissions as Poster Displays. Apologies to those we did not select - it is not necessarily a reflection on your effort but more the limited space available in the programme. Please consider resubmitting an updated abstract next year, and we welcome feedback on our selection processes.

"Working Together" - now an overused phrase at risk of misinterpretation, was chosen as the theme for this conference as a result of member's opinions (and before the Government launched its own mission to achieve this aim). These opinions were gleaned from both our previous conferences and from the Newsletter where the strategy for the PMG has been suggested to be "to promote working together in a co-ordinated and integrated way across the many service boundaries that exist to achieve a comprehensive and seamless service in postural management and mobility". So far, this strategy has been an undercurrent of opinion frequently surfacing but without structure, strength of opinion or agreed way forward. This conference will address these gaps. We plan to achieve consensus views on how to effectively work with our colleges across boundaries and barriers to provide a comprehensive, seamless services in postural management and mobility in all its guises. The Audit Commission's report on aspects of our services, also presented at this conference, will also inform our discussion and influence our actions. We will endeavour to summarise the conference consensus in an agreed plan of action, by whom and when. If we achieve this aim and have a clear directive from the membership the strength of opinion of such a significant, front line group of professionals represented by this conference and informed by the Audit Commission report must surely carry enough weight to facilitate change. Clearly the committee alone could not do all that was needed and we would be looking for assistance from the members to undertake specific, achievable tasks to reach our goals. Like and army of ants, together we will make a difference.

Education

The Newsletter 'Posture and Mobility' continues to go from strength to strength and will do so for as long as you support it with your contributions and the editorial team continue their gentle reminders for these and their imaginative production processes. We have not progressed the business case this year to raise its status to a referenced journal, but will consider this as time permits during the coming year.

The valuable book subsidy, which this year of the new millennium has been raised to £40, is another educational feature of membership for members of PMG attending the conference. Cambridge Books will again have a stand at the Exhibition and I anticipate that books will also be available from other exhibitors for which the voucher is valid. I wonder why non-members who attend our conferences remain non-members with such benefits more than repaying the membership fee.

As in previous years, this conference will contribute to the CPD / CME of individual attendees and this year we have launched the bursary for students. This covers the cost of the attendance at the conference for the student best able to describe the personal and anticipated professional benefits of attending. We had a disappointing response with only one applicant which may well be a reflection of our publicity of the award. The application was a valid one and the bursary was awarded. We look forward to the student's report on the conference in the next edition of Posture and Mobility.

National and International Activity

I have recently taken over from your previous chairman as the PMG representative on the International Standards working group progressing a standard for posture support. I also attend meetings of the various wheelchair standard groups and am able to represent PMG views at these times. I am still getting to grips with what this all means and will in due course report back to the membership and seek feedback/input on the significant aspects of the work.

The Institute for Physics & Engineering in Medicine (IPEM) held a one day meeting in March to discuss the stability of wheelchairs when fitted with a range of assistive technology and the responsibilities of those fitting this technology. The report of the meeting will be published an one of the recommendations was that the PMG was the most appropriate organisation to take forward the actions for further discussion and implementation. I believe this is worthy recognition of the PMG as an organisation able to influence or effect change due in no small part to our multidiciplinary membership. Once the actions are confirmed the committee will inform and consult with the membership and discuss a way forward.

Whizz Kidz have set up an advisory board to guide them in working more closely with the statutory services for the provision of mobility equipment for children and the PMG have been invited to be represented. Julia Cunningham has agreed to be our representative. Whizz Kidz have also applied to be a Millennium Awards Partner to offer new opportunities to young people with disabilities and again have invited PMG to assist and support them This we have agreed to do. It is early days and we will keep you informed of the progress of this activity and seek comments and feedback when requested for these by Whizz Kidz .

Future Conferences

We are involved in the planning of a meeting/conference to discuss transport issues for people in wheelchairs and special seating. Alison Thom is taking the lead for the IPEM Rehabilitation Special Interest Group in collaboration with the Occupational Therapists' Special Interest Group and PMG. We anticipate initially, a one day meeting provisionally set for the 16th of November, in Birmingham, so look out for further announcements.

The next PMG conference will be held in Nottingham on 2nd & 3rd April 2001 with the provisional title "Children of today: Adults of tomorrow". The focus will be on the provision of our services to children, particularly those with severe and complex disability, as an investment for the future. We also want to address how to close or bridge the gap between the relatively co-ordinated services for children and the less co-ordinated services for adults - again, particularly those with severe and complex disability. As usual there will be space in the programme for a range of presentations including free papers, clinical case studies and technical reports. So, after this meeting, please begin your thinking and preparation for the next conference and have your abstracts ready for submission when we call for papers.

The Committee

Finally, I would like to place on record here my gratitude for the enormous amount of work undertaken and commitment demonstrated by the committee on behalf of the PMG. When I was appointed Chairman I said I had a difficult year ahead that would not allow me to fulfil all of my responsibilities. The committee said they would support me and share in the tasks ... and support me they have.

The majority of the work for this and subsequent conferences (including site visits), the production and publication of the Newsletter and the day to day running of the PMG has been undertaken by the other members of the committee, with me getting chased from time to time for my contribution. It is iniquitous to single out individual members, save to mention that this year our conference organisers are BES Rehab, who submitted the best tender for the task. Barend ter Haar, of BES Rehab., has picked up the lion's share of this task and as he is also our Treasurer and Membership Secretary he has had a tremendous workload this year. Thank you Barend and every other committee member. The organisation of the PMG activities is a credit to your efforts.

Next year I will do more! During my Chairmanship, I would like to see the PMG progress the cross boundary, multidisciplinary working so necessary if we are to provide co-ordinated services to the whole person and not just the sitting person. This will involve collaboration and closer working with other representative organisations. I look forward to the outcome of this conference and your guidance on what you see as the best way forward for your organisation, the PMG.

Roy Nelham
Chairman

Roy Nelham

Post Bag

Dear Phil

Re: Posture and Mobility - vol. 10 Autumn 1999.
The product on the front cover is a Radcliffe push handle as fitted to the Shadow Wheelbase, seen from below showing the grub screw locking system.

James Boyd.
Radcliffe

Any more funny photos from the wheelchair race out there? Please send them to the editor if you feel the membership needs to see them!


Is that Alison again?

Winner: of best 'doe-see-doe' was picture 5, of Dave and Alison, taken by Delichon, here it is again in case you missed it!

PMG Prizes Awarded For:

Poster presentation:
£50 to C. Bernard & M. Dyke
"The ups and downs of referrals to a specialised centre"

Clinical case study:
£100 to A. Joyner & M. van Dijk
"Powered mobility for the young child"

Technical presentation:
£100 to Mike Hare,
"Headrests on wheelchairs/seating systems in vehicles"

Free papers:
£100 to L. S. Rose & M. Ferguson-Pell,
"National survey of wheelchair provision to persons with spinal cord injury"

Exhibition trail: Dr Linda Marks

The student was pregnant. She had two femurs of her own, two of her unborn baby, and one in her hands.

Notice Board

Date	Venue	Title	Contact
August 2000			
4 - 7	Warwick Uni.	10th International Mobility Conf.	tel. +44 20 8682 2442
September 2000			
6 - 9	Nuremberg	Rehab 2000	email: info@rehab-2000.de
13 - 14	Wembley	Independent Living London	tel. 01275 836465
27	Stoneleigh	NHS Supplies	tel. 01244 586719 (Tony Brown)
October 2000			
26	Birmingham	RARE	tel. 020 7346 1650
November 2000			
16	Birmingham	Risk Management in Vehicle Transportation for People in Wheelchairs	tel. 1904 610821 email: meetings@ipem.org.uk
27 - 28	Coventry	Quality Services for a Quality Lifestyle (follow up to emPOWERing Partnership conf.)	full details avail. end of June from BHTA
April 2001			
2 - 3	**Nottingham**	**National Conference of the PMG**	**tel. 01723 353177**

TISSUE VIABILITY SOCIETY.

Are you an expert in pressure care? Would you like to learn more and keep up to date with current research in this field? The Tissue Viability Society would like to attract more members from all professions working in this field. Their membership list registers only a handful of therapists and yet many wheelchair therapists feel they have an expertise in this area.

Why? A glance at the Journal of Tissue Viability quickly gives the answer as virtually every article relates to wound care and dressings. There have, however been some excellent articles relating to disability and pressure management, informative research regarding the value of risk assessment scales and their accuracy in specific situations. Amongst the Abstracts from the April conference held in Manchester are presentations relating to: ‘Risk management for people who are at risk.’; ‘The future of nutrition and wound healing: are nutritional risk tools the answer?’; ‘Is there a role for the multidisciplinary approach within tissue viability in the next millennium?’ A number of the free papers were also of value to therapists working in the rehabilitation field - ‘Establishing a protocol for the use of interface pressure measurements in the assessment of pressure-relieving equipment’ and ‘Investigation into the accuracy of pressure sore incidence data monitoring’. There could be more articles and study days of value to the wheelchair therapist if many more joined the society. We are constantly seeking scientific information and clinical-evidence on which to base our practice. The core membership of TVS have a wealth of knowledge based on scientific research of materials and practical experience in their use.

If you are interested in joining, persuade a colleague to join too. It costs in the region of £12-£15 and is good value for money. Information from: TVS, Glanville Centre, Salisbury District Hospital, Salisbury SP2 8BJ.

Mitchells Marvel’s

LITERATURE REVIEWS

The Chailey Approach to Postural Management

Pountney T.E., Mulcahy C.M., Clarke S.M., Green E.M. (2000). Active Design Ltd. Birmingham. Price £25.incl. p&p.

This publication provides a wealth of information based on fifteen years of detailed research and the clinical experience of the multi-disciplinary team from Chailey Heritage. The design and the layout of the text, the absence of jargon and use of everyday language, clear indexing and references all contribute to enabling the reader to access the information quickly and easily. The updated illustrations taken from photographs of children at Chailey, are a great improvement on those in the earlier publications and papers. They help to bring the text to life and add to the enjoyment of using this book.

Assessment techniques and basic principles of postural management are supported by examples taken from clinical practice together with exercises which demonstrate each point. The reader is questioned from time to time to check that learning has taken place and the information is fully understood before moving on to the next stage. Key points are highlighted with statements presented as proposals for debate, with suggested practical activities which will help the reader to understand or experience a specific point more clearly.

Chapter 4, 'Knowledge Base' covers a number of topics including biomechanics, muscle and bone adaptation, neuroplasticity, the sensory experience, surfaces and tissue trauma to name but a few. Several of these areas relate to complex structures and details which may be difficult to fully comprehend, but the style of presentation and use of everyday events to explain even the most complicated matters and processes make this publication of value to all. Those with greater experience and knowledge in this field will find the information supported by up-to-date references which can be used for greater in-depth study.

As stated in the preface, this is intended as a training manual that can be dipped into or read in its entirety. Tucked into a pocket inside the back cover is a set of assessment charts, for use when assessing the levels of ability - lying, sitting and standing.

The authors, the Chailey team and children who have contributed to this publication are to be congratulated. Whilst based on working with children, much of the information is of equal value to those involved with all age groups. Certainly this publication offers value for money and is recommended to all clinicians, whether newly qualified or experienced, who are working in the field of postural management.

Available by post from: Active Design Ltd., 68K Wyrley Road, Witton Birmingham, B7 7BN

Te1:0121326 7506 Fax: 0121327 8807 E-mail: enquiries@activedesign.co.uk

How to access the following reports:

Fully Equipped - Equipment for Older or Disabled People. National report from the Audit Commission. Ref: 1862402132. March 2000. £20 + £1.95 for p&p.

Available from:
Audit Commission Publications
Bookpoint Ltd.
39 Milton Park
Abingdon
Oxon OX14 4TD
tel. 0800 502030 fax. 01235 400454
email: audit-com@bookpoint.co.uk
www.audit-commission.gov.uk

Those working in the NHS should be able to borrow a copy from their Trust.

Evaluation of the Powered Wheelchair and Voucher Scheme Initiatives. Final Report. Commissioned by the NHS Executive & Department of Health to York Health Economics Consortium.

Available from:
University of York
Helsington
York YO10 5DD
tel. 01904 433620 fax. 01904 433628
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