



*this
issue...*

Complex Physical Disability and Postural Management

plus News from Around the World

- Specialist Support Units for 24-hour Physical Management
- Risk Assessment for Sleep Systems
- Linking Service Provision for an Integrated Approach: The Role of a Community Posture Management Advisor
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Editorial

Leading up to the International Conference in Glasgow, this journal has an international flavour and includes articles which give us some idea of the current challenges facing clinicians in different parts of the world. There are articles describing work in Mexico, Malta and Denmark, and it is clear that they are struggling, as we have done for some time now, with how to address the 24 hour picture with clients with complex disability.

Many PMG members have let us know that they would like to encourage a more holistic, interdisciplinary approach to the management of clients with severe and complex physical disability and we have therefore chosen this as the theme for both issues of the journal in 2010. But how do we best provide this service? And who is best placed and qualified to coordinate the needs of these clients? Just listing off the top of my head some of the areas involved – spasticity management, orthotics, postural support in various positions, orthopaedics, mobility, monitoring of levels of ability and degree of deformity, access to communication aids and other technology, pressure management, as well as adaptations for home, work, and school – provides a compelling argument in favour of this being recognised as a specialised area, and that a knowledgeable coordinator is vital to efficiency and client satisfaction. Please read the article regarding specialist support units for 24 hour physical management and let us know your thoughts. Or better yet, write a short article letting us know of innovations in your area to improve the knowledge base and the service provision for this client group.

I have recently returned from 11 weeks working as a volunteer in India – what a challenge!! We were in a

large city about four hours south of Delhi, living in one room in a family house, with basic facilities – cooking on one gas ring, daily power cuts, and going outside to get to the bathroom with only a bucket and jug to wash with, although we did at least have a flushing loo! The most difficult part to cope with was the noise and dirt from the very busy street right outside our window. Drivers in India obviously have a different attitude to ours: in the UK, we feel that it is our responsibility to be aware of everything around us, but in India it seems that the driver's responsibility is to let everyone know that they are there – the consequence is loud, almost constant hooting, day and night! But wonderful images will remain in my mind – passing one of our local cows known as “Mrs. Moo”



Carolyn at work in India

and her baby on our daily walk through the back streets to work, and occasionally feeding her a leftover chapatti. Seeing entire families riding on one motorbike, with the women in their beautiful saris sitting so upright, “sidesaddle”, and the saris never getting caught in the wheels of the bike. The manual handling – the young people with quite severe disabilities either haul themselves or are lifted onto the bus, and are positioned so that the more able ones support the less able ones; interesting to watch them when the bus goes over a speed bump! And of course there is cricket – the children (and adults) play anywhere. I got the impression that it is quite an exciting time in India to work with people with physical disability as there is currently a huge push for inclusion into schools and society in general.

Again, thank you for your contributions. I look forward to seeing many of you at the International Conference.

Carolyn Nichols, Editor

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Letter from the Chair

Hello again – first of all my thanks to our editorial team led by Carolyn Nichols for another excellent journal. I hope you enjoy this as much as I do, and recognise the amount of work that goes into producing a publication of such quality.

We have been going through a very busy time ahead of the 4th International Interdisciplinary Conference on Posture and Wheeled Mobility – the chairs Barend ter Haar, David Long and Bart Van der Heyden have been flat out making sure it will be a very high quality event. See back pages for dates and details, and if you have not yet booked and want more information go to the website www.mobility2010.org. PMG's partners for the conference are the British Society of Rehabilitation Medicine (BSRM), and the Scottish Posture and Mobility Network (SPMN).

Following its success in Warwick last year we have arranged a pre-conference Training Day on 6th June, with half or full day courses to give you a really in depth

learning opportunity across a range of topics with leading practitioners. See page 42 for details, and check the conference website in case of any changes or updates. www.mobility2010.org/workshops.asp

Helen Hislop, deputy chair of PMG, is leading a group reviewing PMG Governance and will be reporting on this at the AGM. This involves clarification of roles and responsibilities of Executive Committee members.

Finally, as a reminder, PMG is run by volunteers and a part-time administrator, Olwen Ellis. I urge you to get involved. If you have ideas about how things might be made better for our membership or our client group please let me, Olwen or members of the Executive Committee know.

I look forward to seeing you in Glasgow.

Nigel Shapcott, PMG Chair

PMG's New Treasurer

When the call went out earlier this year, seeking a replacement PMG treasurer as Henry Lumley stood down, we were delighted to receive an approach from Rakesh Shukla at Croydon Wheelchair Service. Rakesh is a new member of PMG, and will be attending his first conference next month as a bursar, so look out for his contribution in the next issue of this journal! Henry has kindly agreed to continue as International Conference treasurer, with Rakesh taking on the role of PMG treasurer up to the AGM in June. Here, Rakesh writes briefly about himself.

I have worked as a Rehabilitation Engineer at Croydon Wheelchair Service for over 15 months now, and I've enjoyed every moment of it so far.

Prior to this, in 2007, I gained my Bachelor's degree in Medical Engineering from Queen Mary's University London where, for a year, I was also treasurer of the Hindu Society. I gained my Master's Degree in Biomedical Engineering and Medical Imaging at University College London in 2008.

For two years, until early 2010, I was a member of the

National Hindu Students Forum (NHSF) UK, in charge of Sponsorship and Merchandising.

I answered the call from PMG, and have now been appointed the Treasurer on a temporary, co-opted basis, with the possibility of this becoming a more permanent arrangement at the AGM in June, when I hope to be voted onto the Executive Committee.

And, in July, I'm getting married!

Rakesh Shukla, PMG Treasurer

The next issue of the journal will continue the focus on **Complex Physical Disability and Postural Management**. See more detail about this in the Editorial on the facing page.

Articles can be between 500 and 2,000 words. **Deadline for copy is 17th September 2010.**

Please contact olwen.ellis@pmguk.co.uk or Telephone: 0845 1301 764 for information on format etc.

Time to Put the Brakes On

Patsy Aldersea, FCOT

Introduction: *When Patsy Aldersea told me she was going to retire as a member of PMG this year, it seemed an opportune moment to ask her for an article for the journal. Patsy has witnessed and been involved in many of the changes in the fields of posture and mobility over the past half century, and she was a founding member of PMG. For many of you, this article will be a trip down memory lane, and for others an insight into why PMG honoured Patsy by naming its annual keynote lecture the Aldersea Lecture. OE*

When opening the PMG website I am amazed at how it has progressed over the years and how attractive and informative it has become. However, it reminds me how out of touch I have become with current policies and activities relating to PMG. After some soul searching, I decided in 2010 that the time had come to resign my PMG membership.

Whilst still retaining an interest in PMG happenings and still keeping in touch through friends and ex-colleagues, I must admit that it is quite a relief to not have to cope with ever increasing demands placed on those working in the NHS. In consequence of discontinuing my membership, I have been asked to write a piece for the journal: “reminiscing” or “something about the reason for the Aldersea lecture” was suggested! This has truly tested my few remaining brain cells. Asking an older person to reminisce is taking a high risk – it could result in pages of memoirs! I will resist that temptation and endeavour to concentrate more on my professional life.

They say life tends to come full circle and in a way that happened with my work; both my first and my final job were centred on wheelchair users. Following finals in 1958, I was one of six Occupational Therapists selected to represent England at the World Federation of Occupational Therapists (WFOT) in Copenhagen. Apart from having a wonderful time, it was here that I was invited to take up a post at a new rehabilitation centre in Holland. My home at that time was North Borneo (now Sabah) and it was immaterial where I worked so, always keen for new experiences, I accepted. Apart from returning to England for my bicycle and a bag of personal items, I did not come back again to the UK until 1960.

The rehabilitation centre for young disabled people in Holland was more or less based on the work being carried out by Ludwig Guttman at Stoke Mandeville spinal injuries unit. Many of the patients at the ‘Hoogstraat’ in Holland were disabled due to poliomyelitis, others had spinal injuries, and the rest various neurological disorders. Virtually all the patients were wheelchair users.

My knowledge and experience of wheelchairs and their users was virtually nil, and I had little awareness of the issues associated with using a wheelchair. We were still in the days of spinal carriages, and common terminology included wheelchair ‘bound’ rather than ‘user’. Everest and Jennings and Zimmer (very similar) models were issued to the majority of residents at the centre. In spite of the weight of these well-engineered chairs, the paraplegics became proficient in doing ‘wheelies’ to get over bumps and pavements. Because medical care and treatment were not so advanced in those days, there were fewer users with a high level of spinal injury. Many of those with poliomyelitis, due to the wide distribution of affected muscles, were less independent and struggled with the weight of the chairs. My first patient was Annie, aged 10 with poliomyelitis and no English. I managed to become fairly proficient in Dutch, though the guttural sounds forced me to cycle everywhere, as the bus conductors could never work out where I was trying to get to – particularly with the ‘g’ in the middle of Hoogstraat! I learned a great deal about the mechanics of wheelchairs and, more importantly, of the difficulties facing wheelchair users, particularly as the environment in the late 1950s was less geared to disability than today.

Returning to England in 1960 I worked in a variety of posts, initially at the Cumberland Infirmary (Westmorland and Cumberland were still separate counties). Though there was little opportunity to work with wheelchair users, I loved the post as I was allocated the outlying hospitals, one of which was the TB sanatorium on Blencathra. Those of you who visit the Lakes may know the area, sometimes called Saddleback. The hospital management paid for me to attend a car maintenance course in case the rather antique van I drove broke down out on the fells. After about 5 lessons, the young farmers also on the course were building tractors, whilst I was still struggling to find the gasket head – so I gave up and decided I would die in the snow rather than mend my van! Fortunately that situation never arose and the days I visited Blencathra and made home visits to surrounding farms were fantastic.

There were many humorous happenings during this time, but I will fast forward to when I arrived in London at King's College Hospital, one of the few hospitals that held a wheelchair clinic. This had attracted me to the post as well as the fact that it was a leader in setting up a Physical Medicine department shared by physiotherapists, occupational therapists, and consultants in physical medicine, and included a Functional Assessment Unit (FAU) – all very advanced for the time. The Artificial Limb and Appliance Service (ALAS) was responsible for wheelchair provision and, whilst therapists were closely involved in provision of artificial limbs, there were no local therapists and limited medical input into wheelchair provision. The visiting team from the local ALAC (a doctor and a technical officer) ran the clinic, together with a physical medicine consultant and either an OT or physiotherapist. Little attention was paid to the assessments by the hospital team, and their contribution was mainly ignored – quite tense sessions on the whole!

As for many others of us, marriage and children meant juggling with jobs, but I retained a particular interest in neurology and wheelchairs, and was fortunate enough to be appointed as one of three therapists working nationally with the Disablement Services Authority (DSA) following the McColl report (McColl 1986).

The purpose of the DSA was to oversee the re-organisation and transfer of the ALAS to Regional and District Health authorities. The work undertaken for the DSA was far-reaching and demanding, but also offered endless opportunities to work with a range of amazing, enthusiastic, and energetic people from various professions and backgrounds. The experiences of the three therapists varied widely, but as the London-based therapist, I was appointed to the various committees dealing with issues including safety standards, access, training, contracts, vouchers, user groups, and more. The work involved collecting information locally and nationally, and identifying areas of good practice and issues of concern associated with the re-organization. To say it was a learning curve for me is an understatement – sometimes it seemed that I was being overtaken by an avalanche of information.

The DSA gave high priority to producing a training package which was distributed to every region in England, together with an offer of two free training days. I was allocated the task of distribution and of organising training days, which provided further opportunities for meeting colleagues and users, hearing

their views and concerns, and benefiting from sharing their different experiences.

Change affects different people in different ways. For some it arouses enthusiasm and the excitement of new challenges and opportunities, whilst for others it may bring anxiety and appear to threaten their present situation. Both were evident during the re-organisation period, and anxiety amongst clients and professionals increased when the DSA finally handed the baton to the Regional and District Health Authorities. There was also at this time a perpetual under-swell of change and re-organisation affecting the entire NHS and social services, with Trust mergers, boundary changes, and closure of buildings and hospital sites making fragmentation a real threat throughout all services, inevitably resulting in what has become known as 'the postcode lottery'.

The Birth of PMG

In an attempt to reduce this problem in wheelchair and seating provision, the DSA, before finally handing over responsibility to Regional and District Health Authorities, funded a national conference open to anyone involved in, or interested in, future provision of wheelchairs and seating. This was held in Sheffield. I am not sure how others remember it, but I have vague memories of a very well-attended sort of organised chaos – the crowning glory being someone (I believe he has since been deported to Australia!) setting off the fire alarms by using a mobile phone in the hall of residence which resulted in a battalion of firemen arriving with clanging of bells and flashing of lights. Quite spectacular!



Patsy Aldersea in her final job as Manager of Merton & Sutton Wheelchair Service, pictured here with Mark Panton (Clerical Assistant), Mark Knapp (Rehabilitation Engineer), and Denise Baldwin (Wheelchair Service Co-ordinator).

Chaos aside, the conference was a success. The positive outcome was a proposal to hold a regular annual conference. The first of these was in Swansea the following year, where a small group of like-minded, well-motivated people met, with the purpose of setting up a multi-disciplinary national group. And so the PMG was born. Support was given by the already existing Scottish Seating and Wheelchair Group (now Scottish Posture & Mobility Network). Co-operation between the two groups has continued to provide many benefits for all members including training events, special interest meetings, and international conferences.

In 1992 the Department of Health funded a 3 year project to monitor the state of the prosthetic and wheelchair services following the devolution. I had returned to a clinical post at Roehampton and was invited to be a part-time coordinator for the two project committees with direct responsibility to the Minister of Health via the senior chairman, Lord Holderness.

As with the DSA, this opened many new avenues and contacts. Based at the College of Occupational Therapists I had, for the first time in my life, an office and my own secretary. She was a gem and we shared a good deal of laughter alongside the stress. On occasions Lord Holderness would ask me to meet him and a representative from the Department of Health at the House of Lords to report on a particular matter. This would include tea from a silver teapot and a Chelsea bun served by a waiter in the Lord's tea room. Quite a change from my usual standard of living! Perhaps this was why the PMG committee honoured me by setting up the Aldersea lecture! Though I would like to think that the recognition was linked to the work I carried out during the DSA and project time.

The setting up and running of the Posture and Mobility Group was due to the hard work of a small multi-disciplinary team. I was in the fortunate position of having a regional clinical post as well as having contact with NHS regional and district services, national organizations, user groups, and useful individuals through the DoH project. I think that it was due to my being in this unique position that the PMG committee honoured me with the Aldersea lecture. As with many awards it reflects the hard work and efforts of a group of people of which I was fortunate enough to be a member. I am truly grateful to the PMG and to all those who contributed to the work I was involved with at that time. There are too many to name individually and I could be in danger of offending some by failing to

include them, but I very much appreciated their constant support.

They say that "old fishermen never die – they just smell that way". I wonder what old wheelchair therapists do – maybe they just 'roll away!'

I am finding retirement to be an opportunity to enjoy many stress free activities. I love The North and can never have too much of lakes and hills. Our home is well situated as a watering hole or, indeed, overnight accommodation for friends and family traveling on the M6, and I have included photos with this rambling reminiscence which illustrate two of my present interests.

First, my rebellious border collie Jess – wished upon me when my old dog died. I was asked to foster her from the police pound, but no-one bothered to collect her, so she became a permanent fixture. We walk on the near fells every morning before breakfast, come rain, come shine. The views are fabulous: north and west to the hills of the Lake District and Morecombe Bay, known for its quicksands; east to the Howgills and Yorkshire dales; and south to the fells of Lancashire.

The second interest is Bendrigg Lodge. Bendrigg is a unique and outstanding residential activity centre with incredible facilities for disadvantaged young people. It is highly thought of, and I know that some of you have visited with groups from special needs schools. The newly built indoor activity centre includes a climbing wall and cave system used on wet days. Chris Bonnington was so delighted with it that, after the opening ceremony, he donned his climbing gear to scale it and has since brought his grandsons to do likewise.

The programmes are tailored to the needs of each individual group. Apart from zip wires and challenging outdoor facilities on site, these can vary from kayaking to hill walking, riding, caving, and more. All activities are accessible by wheelchair users. Social activities include evenings at the local pub and shopping expeditions. I am a member of the committee and head gardener when not coping with my own half acre stony plot!

With a son in the States and a daughter in New Zealand we travel most years to one or both. Two other daughters are involved with orchestras, providing plenty of opportunity for concert going. Living in a village is an education in itself – never a dull moment.

Though it is a hamlet rather than a village, we have a decent tennis court which a group of us oldies use on a regular basis as well as weekly badminton in the village hall.

I admit to feeling a twinge of envy when I see information about the coming international conference at Glasgow. My first international conference in Dundee had many outstanding and stimulating speakers. It was also an unforgettable social occasion – whisky, bag pipes, and twirling wheelchairs on the dance floor – amazing!

My good wishes to you all and in particular to those who give so much time and effort to making PMG the success it is today.

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Complex Physical Disability and Postural Management

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Wendy Murphy, Specialist Physiotherapist & Independent Consultant,
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Abstract: *This article makes the case for the development of a network of support units across the British Isles dedicated to the 24 hour physical management of people with complex disability. These people, having congenital or acquired disability, are surviving major neurological trauma and living long lives with very complex impairments. The proposed centres would be staffed by an inter-disciplinary, highly specialist and experienced team of practitioners including rehabilitation engineers, medics, therapists, clinical scientists and nurses.*

Keywords: *Posture, complex disability, physical management, support units, inter-disciplinary.*

As a specialist team concerned with all aspects of the 24 hour management of complex disability, we wish to make the case for the development of a network of support units across the British Isles, dedicated to this specialty. We will explain why, in our opinion and that of others, the proposed centres must be staffed by highly specialist and experienced practitioners in the field.

As is well known, at least partly as a result of advances in medicine (in the broadest sense), people with congenital or acquired disability are surviving major neurological trauma and living long lives with very complex impairments.

We have been working in this fascinating field for many years and have accumulated a breadth of knowledge and experience. We are referred some of the most complex problems imaginable, and the practical and theoretical learning gained from each one adds another layer to our clinical 'armoury'. Even so, just when we think that we have seen it all, someone will present to us with problems and difficulties that we have never before encountered. Often, faced with such a case study, it is a struggle to reach a solution, even with all of the practice that we, collectively, have had. How, then, do those who have had considerably less experience cope with the complex issues presented to them?

To illustrate this point, consider the following scenario. Subject A develops a persistent headache and presents to the GP with a set of symptoms. The GP, a generalist, has the skills and knowledge to be able to weigh up the symptoms and to decide whether to prescribe an aspirin,

or to refer on. In the event, the GP decides that there is cause for concern and refers onto a neurologist. The neurologist takes a detailed history, orders tests, assimilates the information, and diagnoses an unusual, deep seated brain tumour.

The neurologist refers to a neurosurgeon who, having reviewed the problem, decides that he does not have the necessary experience to undertake surgery. Subject A is, therefore, referred onto a colleague who works in a highly specialist unit. The neurosurgeon identified to carry out the removal of the tumour has carried out many similar procedures, at first, very importantly, under close supervision from a practised expert, and then gradually progressing to lead the surgical team. That practitioner is, then, best placed to carry out the surgery, including dealing with any complications arising as the procedure progresses.

So what can we learn from this?

In short, practice makes perfect.

If you had an unusual and deep seated brain tumour, you would not want it to be removed by your GP, or a neurologist or neurosurgeon who had never carried out a similar procedure before. You would want such a complex problem to be managed by a senior and highly specialist practitioner, an expert in the field who had 'learnt their trade' through a process of supervised working and repetition of the techniques involved.

Within our field of work, in the absence of such specialist expertise spread evenly across Britain, what

happens currently? (In respect of what follows, it should be made clear that these are personal observations. You may disagree).

Between the three of us, we travel the length and breadth of the British Isles to teach, and to carry out clinical assessments. We see profoundly disabled children and adults who are inadequately provided for in respect of some, or all, aspects of their management. Too many are uncomfortable, in pain, and/or at risk of skin problems. Too many are compromised in terms of their respiratory and physiological health. Too often, their ability to communicate is reduced by their physical environment. It goes without saying that one, or at worst a combination, of these secondary complications results in the progression of secondary problems and an impoverished quality of life.

This state of affairs does not come about because we don't care, or are incompetent in our field of work, or set out to do less than our best.

The problem arises because the provision of physical management for these clients is ad hoc in nature, and patchy in effectiveness. The organisation of services are such that therapists and engineers, who have first learned the basics of their craft in the workplace and then supplemented their knowledge and skills by attending courses, are not able to apply their learning quickly enough or often enough. Therefore they are not able to build on their skills, and the impetus is lost as in the adage, 'if you don't use it, you lose it'. Further, if and when they do see someone with challenging needs, there is a significant lack of established expertise to provide supervision and mentorship, and so they have to work alone, and can be overwhelmed.

At the time of writing, the Heart Unit at the John Radcliffe Hospital in Oxford announced that the unit would close temporarily pending an investigation into the death of four children, which is (it is reported) considerably above the predicted mortality rate. The Times reports that the problem lies in the fact that the unit is small, compared to others around the country. "The (national) review is expected to recommend that units should have a minimum of four surgeons seeing 400 patients a year **to ensure enough skill and experience are pooled and a sufficient number of difficult cases are seen...** The unit at the John Radcliffe,

the smallest in the country, sees just 100 cases and currently has one paediatric cardiac surgeon."

Perhaps some of you reading this might think that people who have severe and profound disability do not require specialist input in the same way as those who need surgery for a complicated heart defect. For the reasons touched on in this article, we would beg to differ. It is our view that we are working with some of the most vulnerable children and adults in the land, whose lives can be significantly improved if we get it right, but can be irrevocably damaged if we get it wrong.

The model of provision envisaged is for, say, six or more centres across the British Isles, staffed by rehabilitation engineers, medics, therapists, clinical scientists, and nurses. All staff will be highly trained and highly skilled. Clients will be referred to the units by any health care professional who determines that the client's needs cannot be met locally. Each unit will have a range of equipment for assessment (for lying, sitting, and standing) and the resources to assess for, prescribe, fit, and issue all equipment as required. All, or most, of the units will provide training to other professionals and familial and paid care givers. They will also offer opportunities for those who have received basic training to 'shadow' experienced experts in the field.

We have the ideas, but do not know how to bring any of this about. Like you, we are all so busy fighting fires that we have no time to reflect and attempt to address the 'bigger picture'. It would be great to hear your views.

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Please ensure that your PMG membership details are up-to-date!

Risk Assessment for Sleep Systems

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Abstract: This article describes a piece of work carried out by a group of Occupational Therapists and Physiotherapists who have formed the Complex Needs Therapy Action Group (CNTAG). The aim of the group is to address issues around the provision of 24-hour posture management and overall physical management of our clients (children and young people) with a complex disability.

The development of a risk assessment arose from the statutory requirements combined with the lack of any similar, appropriate format for assessing risk when considering provision of night-time positioning. The format may not be applicable in other workplaces, but the concept and “risk list” may be of use to those with a similar remit.

Keywords: Risk assessment, posture management, sleep systems, complex disability, physiotherapy, occupational therapy, deformity.

The Complex Needs Therapy Action Group (CNTAG)

This group comprises physiotherapists and occupational therapists ranging in experience from band 6 to clinical specialist who share an interest in the delivery of optimal care to our clients who have a complex disability. This can widely be defined as individuals who are non-ambulant and at risk of deformity and deterioration of musculoskeletal symmetry.

There has been a steady increase in both interest in the subject of night time positioning and in the range of products available commercially which claim to provide the support necessary for the maintenance of symmetrical lying. The broad remit of the group is to look at all aspects of posture management in lying, sitting, and standing. This includes exploring the evidence base around this specialist area of clinical practice. The risk assessment for the use of sleep systems was developed as a response to concerns around the introduction of something relatively new: the protocol for the use of standing frames and supportive seating for the same client group is much more established and consequently the risks in assessment, prescription, and use of equipment are greatly lowered.

Anecdotally, the CNTAG members were aware of a client (not in our locality) who used a sleep system and had died during his sleep. Whilst there was no evidence, or indeed suggestion, that the sleep system had in any way contributed to the death, it was clear to the group members that there was a need to demonstrate an awareness of any risks incurred from using this equipment, and to identify and record the steps taken to reduce risk if the level were deemed unacceptable. Other factors were also giving cause for concern such as the

knowledge that some of these expensive pieces of equipment were being used incorrectly or not at all, which in itself is a waste of resources and, more importantly, a detriment to the client’s posture and alignment.

Sleep System Protocol

The risk assessment described was drawn up as part of a larger project which entailed writing a Sleep System Protocol with the aim of standardising assessment and prescription practice throughout the Healthcare Trust (now Local Health Board). The sleep system protocol is embedded in a care pathway (still evolving) for complex disability. Importantly, the consideration of night time positioning as an intervention should only be arrived at as a result of in-depth assessment and a process of clinical reasoning. The risk assessment should be considered as part of the information gathering process. It is considered best practice to use the Management of Physical Disability 24/7 (MPD24/7), which can be attributed to the work of Pauline Pope, Wendy Murphy, Pat Postill and Dave Long (1990-2007). There are a number of other assessment tools and options available, but few are as comprehensive as this when it comes to clients with complex disability.

Another important point to note is that supporting an appropriate lying position does not always require an actual “sleep system”. The therapist may recommend simpler items such as pillows and t-rolls, or may consider orthoses such as lycra shorts or gaiters. The merits of all available equipment are assessed objectively on a case by case basis. The CNTAG has undertaken a review of equipment on the market, evaluating the pros and cons of each in terms of ease of use, portability, cost, and predicted outcome, amongst other factors.

Identifying Risk Factors

A generic risk assessment was designed with the aim of minimising the paperwork generated as part of the overall assessment. The working party created a theoretical example of a client with various risk factors and worked through a process of quantifying the risk and then demonstrating how it can be reduced if necessary.

An example of a risk factor is overheating, causing febrile convulsion or epileptic seizure. From the assessment process (e.g. MPD24/7), the therapy team would establish whether the client has any history of epilepsy, and whether the pattern is one of seizures at night or is associated with overheating. The process would tease out whether the client is likely to have seizures wherever he or she may be sleeping. A baseline is established so that, should there be any difference during the trial period of the sleep system, it can be shown that a change has been brought about by the introduction of the system. Where overheating is deemed to be a problem, measures such as “air flow” layers, cool gel material, and so on may be optional extras to consider when prescribing the system. A simpler solution might be to suggest lighter bedclothes. These strategies are then accounted for in the section which deals with how the risk can be minimised.

Similarly, the risk of oxygen desaturation needs to be considered. With clients who already have compromised breathing, the ideal scenario would be for a sleep study to take place either in hospital, or at home if community nurses can be present, to monitor overnight “sats” (oxygen saturation levels in the blood). Again it is possible that a client may have the tendency to “desaturate”. This could be unrelated to night time positioning, and it may or may not be helped by the use of supportive equipment. The aim is to establish exactly what affect, if any, the equipment is having on oxygen saturation levels.

Examples of other factors considered in the risk assessment include: skin integrity, incorrect use of equipment, compliance (i.e. will the system be used), gastro-oesophageal reflux (which may preclude positioning in supine), and the possibility of active movement of the client causing injury.

The risk assessment process is based on the format already in use within the Health Board, and therefore enables compliance with organisational procedures and

utilises a framework already familiar to therapists. For each risk assessment factor, the “working risk” is identified and the accompanying key is used to gauge whether the risk is low, medium, high, or unacceptable. Should a high level of risk be identified there is a second form (1b) which then needs to be worked through by the therapy team, and which documents the measures that need to be taken to reduce the risk.

The importance of multidisciplinary input

A crucial element to the success of this process is that it must be multidisciplinary. Every person in the team around the client/child may have a different perspective in relation to the child/young person’s needs. If the therapists aim to introduce equipment which includes a mattress, and the nursing team are prescribing pressure relief, then a team approach is clearly indicated. The client and the family must be kept at the centre of the discussion and the choice of equipment must suit the needs of the family as well as the child/young person. Information gathered in the MPD 24/7 can be shared with the therapists and rehabilitation engineers within the wheelchair service to enable consistency and efficiency related to the assessment, prescription, and provision of all supportive equipment for each client. The opinion of the medical team should be sought regarding issues such as epilepsy, reflux, and respiratory status. Where relevant and possible the orthopaedic team should be included in the discussions: the aim of using sleep systems is to protect body shape, and the introduction of this equipment may inform decisions regarding surgery.

Conclusion

The development of the Aneurin Bevan Health Board Risk Assessment for Sleep Systems underpins the service offered to clients with complex needs, and has been of assistance with clinical reasoning. The group aims in the long term to carry out similar work relating to the provision of seating and standing frames.

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Linking Service Provision for an Integrated Approach: The Role of a Community Posture Management Advisor

Lisa Jayne Ledger, Team Leader, South Staffordshire District Wheelchair Service, IMEX Business Park, Shobnall Road, Burton on Trent, Staffordshire, DE01 2AU

Abstract: *The Community Posture Management Advisor post was set up in 2002 to identify gaps in service provision for adults presenting with a complex and long term condition, and to create innovative solutions. The post came about following concerns raised by the author when working within the local wheelchair service that the 24 hour postural needs of clients were not being fully met. Having worked in this post for the past 7 years, the author feels that there are critical insights to be shared regarding training opportunities and future models of service delivery.*

Keywords: *Posture management, equipment provision, occupational therapist (OT).*

Introduction

The Community Posture Management Advisor post for Portsmouth and South East Hampshire was set up in 2002, following concerns that the 24 hour postural needs of service users with a complex and long term condition were not being adequately met. For example, whilst postural support within the wheelchair was offered by the local wheelchair service, other provision such as related lying supports or static seating were often non-existent. The concern was that failure to employ an appropriate, integrated, and holistic approach to equipment provision was not only potentially putting people at risk, but was not cost effective in relation to healthcare resources. The author was successfully appointed to project-work a post to identify where potential gaps were and to suggest a way forwards. The funding for the post was secured through innovation funds with the support of the professional lead in Occupational Therapy, and was not funded through the wheelchair service.

Method

The author was appointed as a full time project worker to identify what was or was not being provided within health and social care services in relation to posture management and to create potential solutions. Following the results of this post, a successful business case was secured for a full time Community Posture Management Advisor to work alongside Community Equipment Services, Wheelchair Services and Community Therapy Services. The results that are shared within this paper are largely of the author's personal experience whilst working within the post. In addition, in 2008, a small scale qualitative questionnaire (open ended question format) was sent out to lead clinicians who were trained during this time and had worked alongside the Community Posture Management Advisor to gain feedback regarding the post.

Results

The key results fall into two main categories. The first category, key results in relation to service provision, relates to the observations made by the author over many years regarding the current, relevant issues relating to community services. The second category, key results from Community Posture Management Advisor post, is a direct result of the post.

Key results in relation to service provision:

- Disjointed equipment provision for service users within the community setting and resultant 'post-code' lottery
- Lack of continuity of provision from child to adult services
- Emphasis on condition management in the acute, post-acute, and rehab setting, but services distinctly lacking in longer term management
- Reactive as opposed to proactive approach being adopted
- Lack of systematic reviews for long term conditions
- Lack of physical management programmes
- Lack of knowledge and skills in relation to seating and posture management devices by community prescribers
- Lack of basic awareness within the wider multidisciplinary team with respect to posture management principles and its relationship to pressure care and tissue integrity

Key results from Community Posture Management Advisor post:

- £37,000 year-on-year saved as result of the Posture Management Advisor 'vetting' more specialist equipment requests received within the Community Equipment Service
- 22 occupational therapists trained as Link OT Specialists across the locality in Health and Social

- Care settings to act as specialists for seating and posture within their teams, and able to prescribe more specialist equipment options
- Creation of a Link OT Forum to provide ongoing input, and support the Link OTs
 - Creation of a system for direct prescribing of specialist static seating options, including forms, technical specification documents, and stock systems within Community Equipment Services to deal with requests
 - Results of the qualitative questionnaire sent out to link OTs revealed that the majority felt more confident and better skilled to be able to assess a service user with a more complex posture presentation, and refer on to other agencies. All participants felt that the Community Posture Management Advisor role had reduced waiting times for assessment and provision of specialist equipment such as static seating. However, this was not the case with wheelchair provision with many service users still having to wait up to 2 years for assessment.
 - The majority of participants felt that they had a far better understanding of the relationship of posture to pressure care, and were more likely to refer on to district nursing and tissue viability specialists as a result

Discussion

The increasing numbers of people surviving, and the longevity and severity of their physical conditions, continue to highlight the need for additional resource and expertise in the management of severe and complex disability. In addition, with the increasing strain on NHS and social care resources coupled with the demands of the government's quality agenda and 'doing the right thing, at the right time, in the right place' (Darzi 2008), services are having to reconsider how they deliver care, and identify ways of doing things differently within the existing resources.

The Community Posture Management Advisor post was set up to identify how postural care and equipment were currently being delivered for adults who were presenting with complex and long term conditions, and to set up a strategy to deal with the issues raised. As stated above, there were many issues identified, not least that community therapists were not necessarily confident in assessing and prescribing more specialist equipment. In addition, there were no clear avenues for provision of specialist equipment, particularly in relation to static seating and lying supports. As a result of this, the author decided to concentrate initially on seating solutions and designed a 2 day seating course for community

therapists. The idea was that they could become 'experts' within their own teams, interfacing with the Community Posture Management Advisor where necessary. Over a four year period, 22 community therapists from health and social care teams in posture management and seating were trained, and were invited to attend the Link OT Forum on a quarterly basis. In addition, the author worked alongside the Community Equipment Services Manager in creating a pathway and stock of more specialist static seating options. The Link OTs were able to prescribe directly more specialist static seating for their clients. This worked really well because, not only were the community clinicians more confident in their skills and knowledge, but also service users with more complex postural presentations were triaged more successfully, and received equipment more quickly.

However, this was not the case with wheelchair provision because the Link OTs were not able to prescribe directly into the local wheelchair service. This is a critical area to consider with regard to future models. Through working together, with a move to a more integrated approach, and with all key players signed up to considering provision as a whole, the author is confident that further savings could be made and more timely responses ensured. Other aspects to consider are the links between posture and pressure care that need to be made at both a strategic level and grass roots. The author was successful in engaging at Chief Executive and Board Level within the organisation to raise awareness of the issues and, following this work, was invited to be part of the Trust Tissue Viability Strategy and Policy.

In summary, there is still much work to be done in this field, with new challenges around the corner in relation to the personalisation agenda and individuals being in control of their own budgets and consequent equipment. It is the author's belief that if we are to move to a proactive, as opposed to a reactive, approach we need to look towards empowering service users and their carers so that they are aware of posture management principles and strategies, and are able to trigger the responses back to mainstream provision, and to lobby where necessary. In addition, we need to endeavour to put into place training initiatives within health and social care settings so that all individuals are appropriately triaged and assessed, and have their needs met in a timely and integrated manner. There is also a desperate need to collate more evidence in the field of complex disability management, so that we may engage successfully with commissioners regarding future, more integrated, and responsive models of provision.

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Best Practice in Product Design: A User-Centred Approach to Research and Development

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Abstract: A best practice approach to product design and development was used in the development of 'KIT', a new teenage and adult seating system which bridges the gap between modular and moulded seats for users with complex postural needs. Following a user-centred assessment of clinical, technical, and environmental needs, a series of prototypes was manufactured and subsequently evaluated in over 65 clinical trials with 40 wheelchair users. Mechanical and analytical investigations into the seats' strength and durability were performed concurrently to ensure the seat exceeded ISO standards. This user-centred approach resulted in an innovative modular seating system which easily adapts to accommodate and support changing needs.

Keywords: Best practice, complex postural needs, adjustable, teenage, adult, seating system, postural support, asymmetry.

Introduction

The development of assistive technology equipment is very often an iterative process, with new designs slowly evolving from previous ones based on feedback from users, their carers, and the clinicians involved. While all users generate their own particular set of issues, teenagers and adults often present the most extreme challenge for the design of a seating system due to their size, strength, and increased likelihood of postural deformity. Couple this with the far reaching list of functional requirements, e.g. the need for hoisting, to self transfer, to operate power-chair controls, to be transportable, etc, and the chance of conflicting requirements becomes evident. Recent advances in materials and manufacturing methods have not simplified the issues.

While modular seats adapt to changing needs and are the equipment of choice for early years, their planar design means complex postures, with associated pressure or breathing issues, cannot be accommodated. This results in a shift towards the provision of moulded (or contoured) seating during teenage years. The limitations of moulded seats are well known – they are a snapshot in time, providing a static position which is not adaptable to growth or changing needs. Clearly there is a need to bridge this gap between moulded and modular seating.

Although 'best practice', that is the use of a trusted methodology to produce reliably a near-optimum result, has become a widely established practice in clinical medicine, its use in rehabilitation is still unfamiliar, if not unknown.

However, in the field of assistive technology two broad design principles do dominate: first, the end product must be user-centred and, second, 'good design' must meet defined needs appropriately. Starting with a blank design sheet and using these principles as guidelines for a best practice approach, the objective of this project was to develop a new seating system for wheelchair users with complex postural needs.

Methodology

Three years ago a Health Needs Assessment (2005), based on the UK National Institute for Clinical Excellence (NICE)¹ guidelines, was undertaken to review systematically the target population – teenagers and adults with complex postural needs – for a new seating system. A multidisciplinary research team visited a range of schools, centres, and homes in the UK and Ireland, engaging with the main stakeholders – users, carers, and clinicians – to identify a wide range of factors which directly or indirectly contributed to improving posture, function, and comfort. This

¹Now called The National Institute for Health and Clinical Excellence, but still referred to as NICE.

assessment identified three key clinical requirements:

- To accommodate and support a range of back shapes, including the natural S-shape, a fixed kyphosis, spinal rotation, and a kypho-scoliosis
- To maintain the pelvis in a neutral, stable, and upright position
- To accommodate the lower limbs and feet without straining back, pelvic, or leg musculature, such that the head and trunk are kept midline and facing forward

The following technical requirements were identified as important:

- A robust, durable seat which will withstand extended periods of heavy use
- Optimum interfacing with a range of bases: manual attendant, self-propelling, power
- Straightforward set-up and adjustment for growth and changing need

Prototype seat

Converting these user requirements into design objectives resulted in a prototype seat named KIT which, like modular seats, fully adjusted to accommodate evolving needs and yet, like moulded seating, could contour to a variety of physical shapes.

The prototype comprised of:

- A multi-adjustable three-part back support, each part connected to a central spine by a ball and socket joint, allowing freedom to rotate around and translate along the spine

- A unique ‘pelvic cradle’ which firmly grips the pelvis to encourage an upright posture, reduce forward sliding, and promote dynamic postures
- Multi-positional leg guides and footplates which securely accommodate a range of clinical issues, e.g. tight hip adductors, leg length discrepancy, ankle plantar flexion

The next phase of development was an extensive period of clinical trials with teenagers and adults across the UK and Ireland. In order to provide the most challenging situations, therapists were asked to recruit wheelchair users with complex postural and functional needs who were having issues with their current set-up, be it modular or moulded. Consent for involvement in the research was obtained from 40 users (32 using modular seats and eight using moulds), ages 10 to 77 (mean age 27). For each clinical trial the seat was adjusted to maximise posture, function, and comfort. This user-focussed approach resulted in continual alteration and refinement of the initial prototype. Strength and durability were systematically analysed using a combination of finite element analysis techniques and mechanical testing to ensure KIT exceeded standards laid down in ISO 16840-3 (2006) for wheelchair seating. Crash testing was performed to ISO 16840-4 (2009). The seat was interfaced with a range of commercially available wheelbases, e.g. Otto Bock Discovery and Invacare Spectra Plus, and the optimum balance of manoeuvrability and stability determined for different seat-to-base configurations.

User	Age	Key challenges for KIT seat	Rating	Feedback
Ky	14	Maintain shoulders/head in midline. Stabilise pelvis, withstand extensor pattern	16/20	“Head held in alignment for significant period of time”
Or	16	Accommodate severe kypho-scoliosis	17/20	“Maintained posture as well as previous mould. KIT seat better for feeding”
Ti	17	Accommodate windsweeping, ensure head and shoulders in midline	16/20	“The fact that it accommodates the windsweeping so well is a real bonus”
Tm	19	Maintain neutral pelvic position and encourage upright posture	15/20	“Client’s new chair is a great improvement in every way... he looks taller, smiles and eats better”
To	42	Accommodate spine rotation. Allow self propelling	18/20	“Overall the chair is excellent”

Table 1: Results from questionnaires of five subjects using KIT seat for more than six months.

Clinical Audit

The third phase in the development of KIT was a clinical audit of the final design to ensure it met the original clinical and technical requirements. Using the NICE guidelines of 'principles for best practice in clinical audit' (2002), a long-term trial of the seat was carried out with five out of the original 40 users. The five users were chosen such that each one challenged a different aspect of the design, (see Table 1). Four to six months after the seats were issued, questionnaires were circulated to the key therapists and carers who were asked to evaluate five characteristics of the seat: posture, comfort, manoeuvrability, transfers (hoisting), and pelvic position, and to rate them as excellent, good, satisfactory, or poor. These ratings were converted to a single mark out of 20. Scores from multiple assessors were averaged to give a mean rating for each user.

Clinical Outcomes

An equivalent or improved functional position, as judged by the user's therapist, was achieved in 38 of the 40 teenagers and adults who trialled the KIT seat. Two of the 40 users could not be accommodated due to the severity of their deformity and they required their original mould.

The feedback from the questionnaires for the five long term users is given in Table 1. An example of user Ti seated in his original mould and the KIT seat is provided in Figs. 1a and 1b respectively. The ability of the leg guides to accommodate up to 20° of windsweeping allows user Ti to sit with his feet positioned directly underneath his knees and his head and trunk in midline and facing forward. This position is not possible with his mould due to the constraint of his feet being positioned in the centre of the wheelchair. A photo of user Ky in his original modular seat and in the KIT seat is given in Figs. 2a and 2b respectively. Ky has a strong extensor spasm and exhaustively tested the durability of KIT. In addition, the shoulder protraction system ensured his upper limbs could be supported in a functional midline position. Fig. 3 highlights the flexibility of the backrest for user Or, originally a mould user.

Discussion and Future Work

There is currently a lack of guidelines for the development of new assistive technology. Recognising the need for a seating system which pushed the boundary between moulded and modular seating, Leckey were keen to see if a wholly user-focussed approach to research and development would yield a product which met these objectives.



Fig. 1a:
User Ti in moulded seat



Fig. 1b:
User Ti in KIT seat



Fig. 2a:
User Ky in modular seat



Fig. 2b:
User Ky in KIT seat

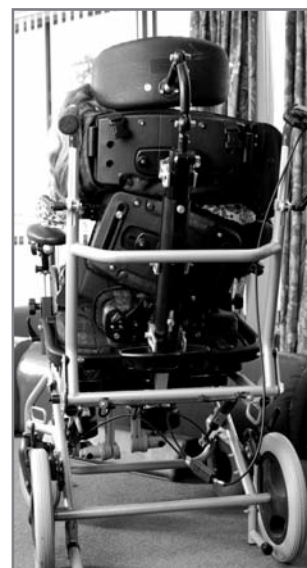


Fig. 3: KIT seat from posterior for user Or

A three-step, user-centred R&D process resulted in the development of a modular seating system with interchangeable, adjustable components which enabled a wider range of the most challenging users to be supported. However, two of the most complex postural shapes, both of whom used moulds, could not be accommodated. This indicates that although the modular/moulded seat boundary can indeed be shifted, some users will always benefit from a bespoke solution.

The aim of supporting the most challenging postures has resulted in a range of innovative features, such as complex lateral supports which, when mounted horizontally, can wrap around a compressed rib cage and, when mounted vertically, can act like a shelf to support a severe scoliosis. Feedback revealed that the pelvic cradle (patent pending) was instrumental in encouraging function and maintaining the improved postures observed. Raising the bar in terms of design goals, and carefully defining the needs, has greatly improved the final outcome.

We recognise it is inevitable that any design can be improved, and are therefore currently working with the major wheelchair and seating services across the UK and

Ireland to collect case study data from a wide range of users which will feed back into our ongoing audit process.

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News from Around the World

Report on the 26th International Seating Symposium, March 2010

University of British Columbia, Vancouver, Canada

David Long, Clinical Scientist, Specialist Disability Service, Oxford Centre for Enablement,
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Abstract: This year I submitted an abstract for a presentation at the ISS and was fortunate enough to have this accepted and for my employer to support my additional costs. The programme, as you may know, is extensive and I was able to attend many sessions. I have laid out below the main points from these which I hope will be of use to practising clinicians and engineers.

Keywords: Breathing, early walking, pressure ulceration, muscle atrophy, dynamic standing, spastic movement, tilt in space, telerehabilitation, digital seating, bariatric mobility, equipment exhibition, paralympic games.

Breathing and upright posture: simultaneous needs. Mary Massery, PT, USA

Take a can of fizzy drink. The aluminium can is weak in isolation but when filled with a carbonated liquid, sealed and having a small pressurised air space directly under the lid, becomes highly resistant to deformation.

Postural control in the human being is influenced not only by neuromuscular and musculoskeletal structure, but also by the internal pressures developed by the pulmonary cavity (lungs and heart) and abdominal cavity (stomach, liver, intestines, bowels, etc). Internal pressure is regulated in three ways:

1. Inter-cavity differential pressure by the position of the diaphragm;
2. Chest pressure by the vocal folds;
3. Abdominal pressure by the pelvic floor.

As a result, it is clear that breathing and postural mechanics should not be handled separately when dealing with posture management, especially sitting and standing. Reflux is also influenced by the ability to manage internal trunk pressures.

Use of anterior chest straps was discussed. It was suggested that such devices can sometimes, especially in isolation, encourage kyphotic postures, undermining the functional ability of the lungs by compromising the diaphragm and intercostal muscle coupling. Other

means of stabilising posture were encouraged such as orientation in space (tilt), use of spinal orthoses, and a varied physical management programme. Also discussed was the use of speaking valves for people with tracheostomies. These valves re-engage the vocal folds, allowing improved regulation of internal cavity pressure by graded exhalation. This can give rise to improved bowel function due to the development of pressure on the diaphragm.

Should we push early walking? Ginny Paleg, PT, USA

Stimulation of the neural pathways in the very young child is crucial to neuromuscular development. Without stimulation, axonal growth of the sensory and motor neurons is impaired and, crucially, the window of opportunity is almost completely closed by the age of six years. There is evidence to suggest that stimulation before the age of two promotes sensory and motor nerve regeneration where there has been damage to the brain, such as for those with cerebral palsy.



It was suggested that there is evidence that nearly all children in the Gross Motor Function Classification Scale (GMFCS) level I, II and III will have developed all the motor skills they are ever likely to by the age of around five years. Of even greater concern is the

suggestion that the window of opportunity for those in levels IV and V is likely to have closed by the age of only two years. Clearly, this has highly significant implications for sitting, lying, and standing. In utero, typically developing babies usually start to move at around 14 weeks. This means they have had six months' practice even before they are born. The infant with a damaged motor cortex is already at a disadvantage at birth.

The presenter uses gait trainers/baby walkers for non-ambulant children from a very young age in order to make the most of the small window of opportunity that exists. It was suggested that up to 3 million repetitions are required for the perfection of some motor skills. Taking walking as an example, typically developing children take around 10,000 steps per day. Therapy sessions are clearly insufficient to achieve this. As a result, family involvement is crucial.

Why is the aetiology of pressure ulcers still unknown? Christian Gammelgaard Olesen, Denmark

The detailed mechanism for the development of pressure ulcers is still unknown. Some pressure ulcers develop in deep tissue, often at the interface with the bone, but the causal mechanism for this can be difficult to determine, resulting in difficulty identifying a suitable means of prevention and treatment. Whilst mechanical loading is recognised to be the initial cause, able bodied persons are subject to high levels of loading that do not lead to the development of pressure ulceration, e.g. riding a bike or sitting on an office chair for prolonged periods.

There is a hypothesis that mechanical loading blocks arterial blood vessels leading to ischemia and resultant cell death due to a lack of oxygen and nutrients. The question is how long it takes for necrotic tissues to form, and how much necrotic tissue is required to form a pressure ulcer. A recent study has shown that hypoxia alone does not lead to tissue damage within the first 22 hours, but that compression of 30-50% strain leads to cell death within a few hours.

It was suggested that the next step in understanding the development of pressure ulcers is to identify and analyse the types of deformation which tissue cells are unable to tolerate (compression, tension and/or shear). Mechanical engineering material analysis techniques have been transferred to the analysis of aspects of tissue trauma and pressure ulcer development. A technique known as finite element analysis (FEA) is used to

predict failure points in any given design, for instance the mount which holds the engine of a car to the body structure. To apply this to people it is necessary to build a mathematical model of the human body, not only the outer shape but the entire structure comprising bones, ligaments, muscles, and tendons. This has already been partly achieved by the AnyBody Modelling System, which was initially developed by the furniture industry, and which currently has around 1000 muscle models. This "body" can interact with an environment allowing the analysis of complex forces such as those found in shear. Many variables can be altered including coefficients of friction, chair size, support elements, orientation of position, etc. The model is currently being validated using motion analysis on a 'real' person seated in a wheelchair. Findings will be published in due course.

Further information is available at:

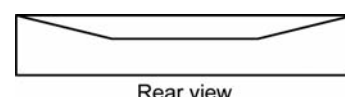
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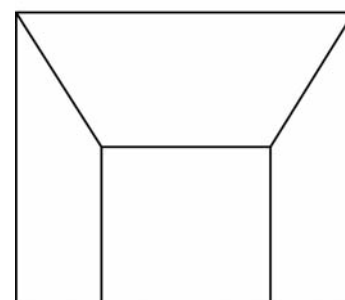
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The gluteal challenge: the development and outcomes of the contour seat base for spinal cord injury patients with significant lower limb atrophy. Charisse Turnbull, Australia

A clinical challenge had been identified where spinal cord injured patients presented with particularly atrophied gluteal muscles of the buttocks and also in the legs resulting in tissue trauma over the bony prominences due to increased loading. It was found that commercially available cushions offered insufficient immersion of the bony prominences.



Rear view



Plan view

A firm foam base was developed in the shape shown in the above diagram. This was placed under a high profile Roho Quadro. The sides are sloped to encourage weight bearing through the greater trochanters. The front is sloped to increase weight bearing through the thighs. The slope angles are adjusted to suit the individual.

A pressure mapping exercise was undertaken which showed improvements in distribution with 13 patients.

Dynamic vs passive standing: investigating the impact on bone mineral density (BMD).**Megan Damcott, USA**

Funding for equipment in North America is granted by insurance companies who are making increasing demands for scientific evidence to support applications. Increasingly, funding for passive standing frames is being denied on the grounds that there is insufficient evidence to support their use, particularly in relation to the claim that they maintain or slow down the reduction in bone mineral density which has a direct impact on osteoporosis and the risk of fracture.

This has prompted the presenter to develop an auxiliary device to turn a passive standing frame into one which induces dynamic loading/unloading, i.e. movement is induced to mimic the effects of walking. It is generally accepted that this is the mechanism for stimulating bone development.

The device developed comprises a platform for each foot which is moved linearly through a distance of 10mm. A greater distance would cause positioning difficulties in a standing frame which was not designed to allow movement of the occupant in this way and may also place inappropriate forces on unstable hip joints. Pneumatic actuators were selected as the noise was said to be too intrusive when using electrical actuators and caused a startle reflex in some children. Programming of the device was achieved using MATLAB software. Parameters required are weight of the child and the duration of the session. The actuators move at a speed of approximately one complete cycle per second. Load cells measure forces applied.

An initial six month study has been started with sixteen children aged 2-9 years using the dynamic stander for 30 minutes, five days per week.

Initial indications for measurements of bone mineral density show an increase for those standing dynamically and no change for those standing passively. The results cannot be reported fully until the study concludes.

Recognising spastic movements: facilitating safe control of devices. Dr Jeff Morris, Clinical Scientist, Wales

Many people use switch interfaces to control a variety of electronic assistive technology devices. Difficulty can arise where spasms cause unintentional activation of the switch. This might cause inconvenience at best and significant safety issues in the case of a powered

wheelchair driven using switches.

Volitional and non-volitional movements have different patterns in terms of their duration and forces applied. This study looked at ways of identifying these patterns and the production of electronic filtering of non-volitional movement. This was achieved by modifying a 'Buddy Button' switch to incorporate a load cell. The size and duration of the applied force can then be measured and filtered if identified as non-volitional. Whilst the filter is based on 'normal' patterns of movement the design incorporates user controls to adjust the 'acceptable' envelope. Initial indications show that this is an effective method of enabling switch access for people who experience spasm. Further research using the switch design will be conducted.

Draft recommendations for training and use of power tilt systems. Dr Stephen Sprigle, PT, USA

Posterior tilt in space has long been used to offload the buttocks to protect skin. Some argue that it is necessary to tilt to as much as 55 degrees to the horizontal in order to off load the bony prominences truly. A survey undertaken by the presenter's department has found, however, that in many cases people feel unstable at such extreme angles, that it can be disruptive to everyday living and can lead to feelings of embarrassment in social settings.

The presenter suggested that tilting to only 20 degrees significantly reduces shear and that such an angle is sufficient to increase blood flow compared to the upright posture: at 15 degrees there is an increase in blood flow at the ischial tuberosities of 8%, at 30 degrees there is a 24% increase and at 45 degrees an 84% increase.

It was also suggested that many people do not use the tilt feature fitted to their chair. It was hypothesised that this is due at least in part to a lack of education of users and carers. The following guidelines were suggested:

- Pressure mapping can be used to demonstrate visually the off loading process, even with small amounts of tilt.
- The occupied chair should be taken through its full range of tilt.
- A check should be made to ensure the user can use switching at full tilt.
- Written instructions should be provided, complete with pictures.
- The environment should be assessed to allow use of tilt e.g. putting the television higher up.

There was a suggestion from the floor that one should align the need for tilt with the need for taking medicines. One must be careful, of course, that this is done appropriately and not without due consideration of the implications and level of understanding of the user.

There was also a discussion around the need for a head support when tilted. It is sometimes the case that people do not like having a head support fitted. At these times it might be appropriate to use a rolled towel or small pillow which can be stowed readily.

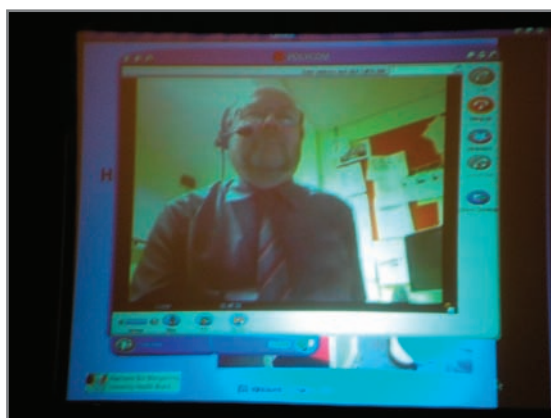
Summing up, the presenter questioned whether asking people to tilt is like asking them to stop smoking, to drink less, to exercise more. Tilting might be more disruptive than we care to acknowledge.

Telerehabilitation in rural areas using commercial broadband. Nigel Shapcott, Consultant Clinical Scientist, Wales

Your Chairman demonstrated the possibilities of undertaking remote clinics using teleconference technology by conducting this presentation from his office in Swansea. The image below shows how it is possible to see and speak with someone in another location. Skype is generally not permitted over NHS networks due to concerns around data security, hence the requirement to find alternative methods.

Nigel was able to show powerpoint slides and to do a “live” pressure mapping exercise on himself which was displayed in real time in Vancouver. There were no delays with timing and a single roving microphone was used to take questions from the floor.

Whilst it was acknowledged that use of technology in this way cannot totally replace hands-on clinical assessment, it was clear that certain clinical tasks could be usefully undertaken remotely.



View of the presentation in Vancouver

Digital seating service. Lorna Tasker, Clinical Scientist Advanced Trainee, Wales

This presentation followed on from that delivered to the PMG National Training Event in Warwick in 2009. Two further developments were discussed:

1. Covers for custom contoured seating are often difficult, and hence time consuming, to make. They may also not be the most aesthetically pleasing. Fashion design software is being trialled to aid the process, using the digitised image taken from the cast.
2. Digital scanning requires substantial financial investment in equipment. Digital camera technology has advanced significantly in recent years. An exploration of using this to produce photogrammic images of seating casts is being undertaken. If successful, costs of capturing the image digitally would be substantially reduced. The work is being carried out by James Nasrat, Clinical Scientist Trainee, as part of his MSc project.

The Rehabilitation Engineering Unit will report further on these projects in the future.

Bariatric seating and mobility: considering the options. Jean Minkel, PT, USA

The term bariatric applies to persons for whom obesity is the PRIMARY impairment. Otherwise, the term should not be applied. Where a person becomes obese, this has often been found to be linked with sociological context e.g. local shops do not sell healthy foods.

Manual wheeled mobility is more likely to induce physical activity than powered mobility, but is limited by the ability to push an increased load. Additionally, self propelling wheels may make the wheelchair too wide for doorways. Where manual mobility must be used, it is necessary to move the rear wheel axle forwards to allow for the anterior body mass. The front castor wheels may also need to be moved forward to resist forward tips.

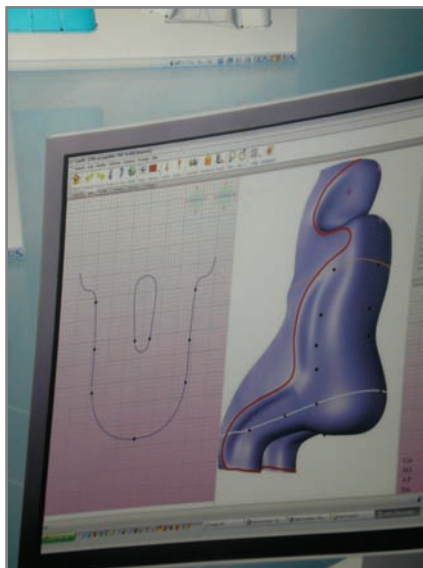
Powered chairs tend overall to have smaller widths. Mid/front wheel drive chairs are often better, but weight can be placed too far forward, pushing the (fixed) front stabilisers onto the ground, making turning difficult and inducing rocking in the chassis. It is also necessary to consider that anterior tissue can obscure the feet and even the joystick.

Photographs from the equipment exhibition

I have included here images of equipment I discovered in the exhibition. There were, of course, many examples of what we might find at an exhibition in this country, but these are the more interesting topics.



Digital seating from Vorum Research Corporation, Canada (one piece support for severe joint range limitation)



Digital seating from Vorum Research Corporation, Canada (software demonstration)



"Dynamic" back support, pivots about the central vertical spine (available from Tendercare in the UK)



Front mounted anti-tipper (non swing-away footplate hanger)



Roho cushion for use with a commode



'Prone' powered wheelchair with occupant joystick

Opening of the Paralympic Games

I was given the opportunity to attend the opening ceremony of the Paralympic Games 2010 which took place in an indoor 60,000 seater stadium. It was a remarkable event which was extremely well supported by the home crowd. The teams from around twenty countries paraded across the stadium. The Canadian team entered last and were greeted with enormous enthusiasm.

Footage of the games is available at:

- www.paralympicsport.tv
- www.vancouver2010.org (including Winter Olympics)
- www.disabled-world.com



Entry of the Canadian team

The full syllabus for the proceedings of the symposium has in previous years become available on the web and it is anticipated that this will continue. See: www.interprofessional.ubc.ca In the mean time, if you would like more details on specific references please email me. Thanks.

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Postural Management 24/7 – What is That?

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Abstract: *The clinical specialty related to providing mobility, seating, and standing for those with physical disability has become well established in Denmark over the past 10 to 15 years. However, awareness of the importance of night-time positioning has only recently arisen. This article describes the early development of that field, the importance of assessment, the identification of design criteria for relevant assistive devices, and the importance of family involvement in the sensitive area of sleep.*

Keywords: *Posture management, assistive technology, night-time positioning.*

In Denmark, the process of assessment and provision of seating for people in wheelchairs has developed to be an area of specialisation among OTs and PTs during the last 10-15 years. Additionally some users – especially children – have regularly used standing frames as it is common knowledge that this is healthy for bone development, and some activities are easier to do in standing.

However there has been little knowledge about, or interest in, how wheelchair users are positioned during sleeping hours. Slowly interest is rising. At the Nordic Seating Symposium in Iceland in May 2009, several speakers shared their knowledge about positioning wheelchair users during the night in order to prevent them from developing deformities that would make it more difficult to sit during the day and live their everyday life.

Lately two courses have been held by the Danish Centre for Assistive Technology in order to spread knowledge in Denmark about positioning 24 hours a day. The courses were immediately overbooked because of massive interest in the subject.

Purpose of 24 hour positioning

The purpose of 24 hour positioning is to maintain the current function and, at the same time, minimize the risk of secondary complications. The aims are to maintain the body in a straight and functional position, to stabilise the segments of the body in correlation with each other and the supporting surface, to control the forces which affect the body's position, and to improve comfort throughout a 24 hour cycle.

But when is it necessary to investigate how a wheelchair user is positioned during the night? This is important when the child or adult is not able to change position by themselves, and/or when the user spends a long period of time each day in an asymmetric position, or if the user is controlled by spasticity, reflexes, and involuntary movements.

A simple exercise to demonstrate the importance of 24 hour positioning is to ask the user what length of time he sits in his wheelchair each day and for how long he lays in his bed. Put the results into a diagram and it will become very clear: the user perhaps sits in his chair for four hours in the morning and four hours in the

afternoon, and the rest of the time he is lying down. During that time secondary complications can easily develop if the user is not properly positioned.

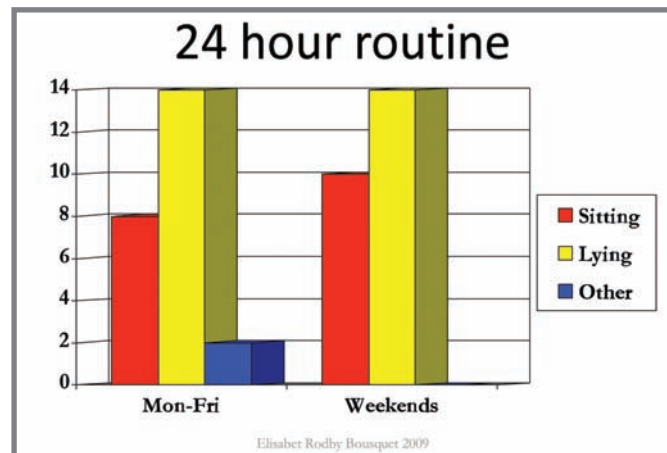


Fig 1. Example of a user's 24 hour routine
(Picture: Elisabet Rodby Bousquet)

Assessment for night-time positioning

The aim is to have the head in the middle, symmetry in the pelvis and the trunk, the legs symmetrical in relation to the pelvis, the arms resting along the sides of the body, and an even distribution of weight. However, to define an appropriate, stable position and a position which is comfortable at night and during sleep, it is essential to assess the user's range of motion in order to ascertain which joints are flexible and which are limited.



Fig 2. During the course it is useful to practice examination techniques on each other

Supportive devices

In order to maintain the desired position, defined during the assessment, the therapist may use support cushions, cushions to keep the legs apart, and perhaps more advanced technical devices such as thorax support. One or more trials with these devices may be necessary in order to establish the most effective position and support, while at the same time helping the user relax as much as possible for sleep.

In Denmark there are not a lot of cushions and other technical devices on the market for this purpose, so one must be somewhat creative and use what is within reach. Apparently the same is the case in Norway. This became clear during a recent project (Posisjonering i et 24-timers perspektiv) aimed at developing methods to evaluate and implement postural management 24/7 with children: participants needed to develop custom made, individual cushions and other devices as no standard equipment was available on the market. The study findings emphasised that the criteria for this equipment include: user friendliness, aesthetic design, no risk in use, and the assistive devices had to be easy to clean.

Liaison with, and support for, the family

In the project it also became quite clear that the way the children were sleeping during the night was a very private matter within families. Therefore a special focus on the parents' reactions was necessary, so that the children really were positioned well during the night. As a result of this, a small leaflet was developed to give the parents appropriate information.

Summary

So Postural Management 24/7 means to be aware of the need of some wheelchair users to have their body appropriately positioned both during the day in a chair, or in standing, and also during the night in bed, in order to keep their functions intact and to prevent deformities.

The focus in Denmark has until now been the position in seating, but slowly interest in the usefulness of positioning the user during the night is increasing. One of the participants in a course on the subject, Tove Sand Jensen, made this comment on her practice following the course: "After the course I have an easier way to examine my users – and now I am more aware of the importance of night positioning than before."

References:

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Setting up the First Independent Living Centre in Malta

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Abstract: *The National Commission for Persons with Disability in Malta (KNPD) has obtained funding from the European Regional Development Fund (ERDF) to construct and equip an Independent Living Centre (ILC), and from the European Social Fund (ESF) to train professionals in specialised aspects of independent living. While the concept of independent living is broad, this project will focus solely on increasing mobility, and the ability of persons with physical disabilities to engage in activities of daily living, employment, and education.*

Keywords: *Independent living, mobility, assistive apparatus, training, assistive devices*

In recent years, disability has become a human rights issue, with priority being placed on the full integration into society of persons with disabilities. Employment is key to this integration. For all citizens, quality of life, social well-being, and personal fulfilment are enhanced by inclusion into the mainstream job market (Madrid Declaration, 2002). Vocational training and employment are recognised as central to social integration for all citizens, including those with disabilities (Hizette, 2002). Employment allows the disabled person to move away from being dependent to becoming an active participant contributing to society.

Most often, it is not the person's impairments that prevent her/him from finding and keeping a job, but obstacles that continue to exclude persons with disability from society, such as the lack of accessible transportation, accessible buildings, appropriate assistive aids and equipment, and access to services. The United Nations Convention on the Rights of Persons with Disabilities (2007), of which Malta is a signatory, requires State Parties to take effective measures to ensure personal mobility and the greatest possible independence for persons with disabilities. One of the aims of setting up the first Independent Living Centre in Malta is to equip disabled persons with the necessary basic tools to enter and function better in the world of employment.

Mobility

Mobility is an essential aspect of daily life and the independence to drive a car or travel as a passenger is valued by all. Disabled persons in Malta have difficulty accessing public transport and most of the time must rely on family or friends to be taken to school, work, or social activities. Because of these difficulties, many disabled people remain excluded from employment opportunities, access to education, and a social life. Consequently, they

experience the effects of insularity even if they are not geographically isolated from urban areas.

The Local Situation

A study carried out by the National Commission for Persons with Disability in Malta (Research and Development Division, Employment and Training Corporation, 2005) found that, in the age range from 20 to 59 years, only 24.4% of people with disabilities were employed (as compared to 60.2% of the general population). In this same study, the results showed that approximately 15% had no income, while half had an income of less than €466 a month, i.e. €93 less than the national minimum wage. More than a third of these persons received a disability pension. This all means that, financially, they probably depend heavily on their families. Additionally, 35.5% of the participants claimed that they would need transport to attend a training course and 30.1% would need a place with physical accessibility. 65.7% reported that they would need to be trained in order to be able to work.

One of the recommendations that emerged from this study was that "there should be more support and training so that persons with disability in Malta can be part of the labour market..." (KNPD, 2004).

Mobility and assistive technology needs

Disabled persons who have mobility problems in Malta are particularly affected. Public transport is inaccessible and private adapted transport services are costly. There are no mobility centres where one can have a professional assessment and receive the relevant advice and training. At present, persons with mobility problems in Malta are sporadically assessed by therapists in hospitals for their mobility solutions, and generally they have to order adaptations for their cars or vans without

having tried them out first. This means that, all too often, people order equipment which does not suit their needs.

The same applies for assistive technology and equipment such as wheelchairs, seating solutions and aids for daily living. Local suppliers do not stock a wide variety of such equipment, with the result that customers have to order out of a catalogue and, again, money is wasted on unsuitable equipment. At times, persons with disability who need a more specialised assessment choose to go to mobility centres abroad, but this is a very costly alternative. One of the aims of the proposed independent living centre is therefore to provide local professionals with access to standardised assessment technology, rendering the assessment more objective and the subsequent advice more evidence-based.

In 2004 the author carried out a study visit, funded by the EU Leonardo Programme, to the Disabled Living Foundation (DLF) and Queen Elizabeth Foundation (QEF) Mobility Centre in the UK. The purpose of the visit was to observe the running of such centres in the UK and the procedures for standardised wheelchair, seating, and driving assessments, in order to identify the human and material resources necessary for setting up an independent living centre in Malta. Another aim was to explore the possibilities for further training of professionals in similar centres in the UK. KNPD had become aware of these needs through feedback from disabled people and professionals working with them, through the studies referred to above, and through two local studies (Powell 2005 and Lenicker Muscat 2007) that researched the need for independent living services in Malta.



Joseph Camilleri, Chairman of the National Commission Persons with Disability; Vickie Gauci, Project Leader, Anne-Marie Callus, Executive Director of the National Commission Persons with Disability; Mary Rose Meli, Project Manager.



Outside the new Independent Living Centre, March 2010.

Aims of the Project

The Independent Living Centre will include a mobility centre, and an equipment demonstration/assessment centre, part of which would be the wheelchair and seating clinic. The ultimate aim of the project would therefore be to empower persons with disabilities by giving them the basic tools and skills necessary to find and keep a job without unnecessary problems with regards to assistive equipment and transportation. A second phase of the project will consist of providing training for healthcare professionals in order to enable them to offer a better service to disabled people in Malta. The training will include participation in courses abroad and visits by foreign experts to Malta. The training will be mainly aimed at occupational therapists, physiotherapists, and driving instructors.

Conclusion

The setting up of an Independent Living Centre targets the need for promoting a more independent life for disabled persons in Malta in order to help ensure that they enjoy the same level of independence as that of many of their European counterparts. This is in line with the priorities set by the European Union's Disability Strategy as well as Malta's National Action Plan against Poverty and Social Exclusion.

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The S.O.S. Workshop Project at 'Un Nuevo Amanacer' in Mexico

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Abstract: Gordon McQuilton, Managing Director of Specialised Orthotic Services, explains his company's involvement with 'Un Nuevo Amanacer' a disabled children's charity near Monterrey, Mexico. S.O.S. first became involved with the institute about 4-5 years ago, by funding a shipment of redundant seating and mobility equipment from the UK to Mexico. A recent visit to the institute has resulted in SOS now sponsoring a project to redevelop the institute's mechanical workshop.

Keywords: Charity, special seating, Nuevo Amanacer, rehabilitation engineering workshop, disabled children

Un Nuevo Amanacer, which means "New Dawn" in Spanish, was started many years ago by the parents of two disabled children. Since that time the institute has developed and now provides a really effective clinical service for many disabled children and families in Monterrey and further afield in the north of Mexico.

S.O.S. was first introduced to the institute by Sarah Davies, a UK Physiotherapist who has been actively helping the institute for many years, and has achieved great things in establishing a wide range of effective therapies and clinical input. At the time, Sarah was busy collecting old seating and mobility equipment and needed funding for a container to ship it all to the institute. I decided that this was something that S.O.S. could help with, so we funded the first container and our friendship with the institute began.

Last year, at Sarah's request, I decided to visit the institute to see if there was any further help that S.O.S. could offer. So, for two weeks in August 2009, my family (wife Claire and daughters Philippa and

Margaret) and I worked at the institute, and it was a great experience for us all. As S.O.S.'s forte is special seating, it seemed logical to use this expertise to help the institute further, but to find out how we could best do this we needed to see things first hand. It's not until you see how



Fig. 1. Gordon with the workshop team (left to right) Rueben Carillo (Upholsterer), Jose Juan de Leon (Engineer), Gordon McQuilton (S.O.S), Victor Rodriguez (Technician/Welder), Jose Luis Rodriguez (Technician), Don Juan Cruz Garcia (Technician)

little people have that you really understand how lucky we all are. In the UK we really do not appreciate the services we have – I suppose we have all grown up with the Health Service and now just take it for granted.

The facilities at the institute are very impressive, and the enthusiasm of Fabiola Barron, the Director, and her staff captivate you as soon as you walk into the building. We were all soon in the thick of it, helping with assessments for special seating, and I became heavily involved with the guys in the workshop (Fig. 1), responsible for making the equipment. I discovered how valuable the equipment in the container was, as this is used on a regular basis to provide seating and mobility equipment. However, I quickly realised that the facilities and equipment in the workshop could not give the guys all the help they needed. They were really up against it, trying to meet the huge demand from the seating clinics which are held on a daily basis (Fig. 2).

In addition, there was the practical problem of working in the heat – with temperatures reaching 95 degrees outside, the workshop was like a furnace. Trying to run the workshop in that heat was almost impossible – trust us to go at the hottest time of the year. I will never complain about the cold again!

There was a serious lack of equipment as well: one hammer was used by all five guys and other equipment was very old and worn. Something needed to be done to give the workshop team what they needed: a well equipped, efficient workshop. It was at this point that I



Fig. 2. A Seating Clinic at Un Nuevo Amanacer (left to right) Paulina Velazco (Occupational Therapist), Marcella Lopez (Carer), Marie Carmen Escobedo (Client), Jose Juan de Leon (Engineer)

decided to start the S.O.S. Workshop Project to fund a complete revamp of equipment within the workshop and reorganise the layout.

The project is now in full swing. Reports from the team at the institute suggest that they have been working hard and I am really looking forward to returning and seeing how things have progressed.

If any PMG members have old equipment to donate, please let us know, as we are constantly collecting and storing equipment for the next shipment.

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PMG Annual General Meeting

Monday (evening) 7th June 2010

The PMG Annual General Meeting is to be held at the Scottish Exhibition and Conference Centre (SECC) in Glasgow on Monday, 7th June 2010.

NB: Please bring with you to the meeting the Agenda, Accounts and Minutes enclosed with this journal

The meeting will commence shortly after the end of conference proceedings, at 5.30pm.

Please contact PMG vice-chair Helen Hislop if you wish to add an item to the agenda.

Email: Helen.Hislop@haringey.nhs.uk

Alternatively, go to the PMG stand in the exhibition hall at the SECC on Monday 7th June, and one of the committee will find Helen for you.

Inclusion21 Ltd: Promoting Diversity in the 21st Century

Kevin Fitzpatrick, Managing Director, Inclusion21

Abstract: *Inclusion21 was set up in 2004 with the intention of tackling social justice issues. It offers support through training and consultancy to any individual or organisation that is serious about defeating discrimination, or creating real opportunities for social inclusion, or understands the principles of dignity and respect and wants to apply them. Inclusion21's managing director, Dr Kevin Fitzpatrick, has 36 years direct experience of disability and the issues affecting disabled people. A former university teacher, he is an associate of the Welsh Institute of Health and Social Care at the University of Glamorgan. He chairs an advisory group to Health Commission Wales, as well as the board of trustees of St David's Children Society adoption agency, and the board of trustees of Arts Care Cymru. He was appointed Disability Rights Commissioner for Wales at the DRC's inception in 2000, staying in this role until the Commission ended in 2007. Here, Dr Fitzpatrick describes the ethos and work of Inclusion21.*

Inclusion21 believes in the right of everyone to have the dignity and respect that each human being deserves, and "in the same amount". This latter is important because it is not often recognised as a central plank of delivering dignity and respect, rather than merely paying lip-service to the ideals. Affording each person dignity and respect in the same amount, just because they are human beings, is not difficult. No-one deserves less. But what many individual citizens often miss, as do businesses and organisations, are the gains to be had from this simple approach.

So, we offer pathways for every citizen in every way of life to promote the dignity of, and respect for, every other citizen, and to understand the benefits that accrue to all as a result. We also offer businesses, and all kinds of organisations, support for their efforts in this direction which helps create better outcomes for their 'customers', better workplace relations, better productivity, and increases to their bottom lines. It is no accident that the 50 top earning companies of the FTSE100 have sophisticated diversity policies in action.

Organisations are often surprised at how little it costs to make adjustments: changes to attitudes and, when necessary, physical changes are most often cost neutral or at minimal expense. We are in the business of finding solutions for individuals, businesses, or any enterprise, tailoring our responses to their needs and demonstrating the cost-benefits that come alongside this approach to customer care.

Our training courses challenge people to think for themselves and, when appropriate, to think differently about their attitudes and experiences. Our starting position recognises that discrimination can be a tricky subject. Not many people like to think of themselves as discriminators, or even potential discriminators, and when offered the opportunity to examine their working

practices, for example, they can quickly 'get' how small changes make big differences to their customers' experience. The people for whom anti-discrimination laws are designed are, thankfully, fewer in number than those who simply need an opportunity to think differently. But discrimination continues, and so it is heartening how many of our clients have that penny-dropping moment: 'ahhh, now I get it!' is a familiar result.

In a safe, non-judgemental environment, participants in Inclusion21's training courses can explore all aspects of discrimination and even their own prejudices. If everyone has prejudices of one kind or another, some of these can be fairly harmless, but some of them lead to discriminatory and even damaging behaviour. We discuss where our prejudices come from, and which ones can lead to discrimination that is against the law. We then try to equip participants with the skills and knowledge to avoid such behaviours in every situation in which they might find themselves – work, leisure, community relations.

Inclusion21 works in various areas of health and social care – with users, providers, commissioners, and other health and social care agencies. We support private business, the third (voluntary) sector, universities in various ways and in a variety of settings, and our work with local authority and government training initiatives is ongoing.

Inclusion21 does not provide participants with rule books. We work on the basis that if training is to be successful, participants must "own" the issues and commit themselves to thinking and learning about these matters after the course is finished. In each situation we work from an outcome-based perspective, so our first question is always 'what outcomes does the client envisage?' Then our job is to map the route to those outcomes. We discuss which of the desired

outcomes will result in positive change, and work supportively with our clients to promote diversity and to achieve better customer and business outcomes through doing so.

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Wheelchair Service Guidelines for Less Resourced Settings

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Abstract: In October 2006 a consensus conference on provision of wheelchairs in less resourced settings was held in India. The result of that conference was the production of the WHO Guidelines on provision of wheelchairs in less resourced settings. The practical tools to turn these guidelines into service provision are now being developed. The aim of this process is to find innovative ways to establish standards for quality services in areas of huge need but few resources.

Keywords: Innovation, standards, service provision

Wheelchair users have been involved in every step of this process, keeping their needs and views central to service provision. This keeps the focus on people, rather than the service.

The resources, which are still being developed, will be downloadable from the World Health Organisation (WHO) website in November 2011.

Resources will include:

- Content map
- Two week training package which can be delivered as a whole, or individual modules selected depending on the training needs analysis
- Trainer manual
- Reference and support materials
- Best practice video, which will help maintain consistency in the quality of training across different

trainers. It will also include individual testimonies about the importance of the information and skills being taught, reminding the participants that the client is central to this process and a key member of the team

- Competency assessment

Further details on the Guidelines, service delivery and training methodology will be presented by Motivation at the International Posture and Wheeled Mobility Conference, 7th – 9th June, Glasgow.

References

WHO Guidelines on the Provision of Manual Wheelchairs in Less Resourced Settings. 2008.

Contact details for Sarah Frost:

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PMG's Small Research Study Funding Scheme in 2010

At its first meeting of 2010 in January, the PMG R&D sub-committee approved funding for a new research study being undertaken in the London Borough of Haringey by Helen Hislop:

How do wheelchair users and their carers want to be involved in making decisions about their equipment at the wheelchair service?

The next deadline for submission of outline proposals is **30th September 2010**.

For further information and to submit a proposal online, go to:

www.pmguk.co.uk/Research/Information

Reports and Reviews

“Look Me in the Eye” – The i2i Head Support

Course Presenter: Leslie Fitzsimmons

Review by Joanne McConnell, Business Manager, Mobility Solutions, Otto Bock Healthcare PLC,
32 Parsonage Way, Englefield Green, Egham, Surrey, TW20 0LD

Abstract: *This feedback is long overdue, as I attended this highly motivating, one-day course back in June 2009. I must have been impressed, as I have kept my word and am writing this up on Easter Sunday (the deadline for articles has long gone, and I don't want to upset the new editor!). If circumstances had been different I would have written this for the last journal, but with a new job and massive learning curve ahead of me at the time, it has taken me until now to put into words my experience of the course.*

I was grateful to Whizz-kidz for funding my attendance, and shortly afterwards I arranged for all the Whizz-kidz therapists to have a presentation of the Stealth range of accessories, and in particular the i2i, as I was so impressed by the function achieved with this head support, and knew that some of the young people we were assessing would benefit from it.

Keywords: *Head support, neck support, functional head position, eye function, swallowing.*

I was delighted to have an opportunity to attend this course, as I had heard some excellent feedback from therapy colleagues who had attended it during the PMG pre-NTE training day in 2008. In this time of difficulty in obtaining funding for courses it is crucial to know that the funding you are obtaining (or spending yourself) is going to be money well spent, and that the course will be of value to you. This training opportunity was hosted by BES at a very reasonable price at several venues across the UK. The highlight was that Leslie Fitzsimmons was delivering the course; she is a physiotherapist from the USA, and the brains behind the design.

The box of spare bits

It was during my eight years working as a paediatric OT in Worcestershire that I first discovered the “box of spare bits”. If you have worked in such a department you know what is in this box. It comes out almost daily, and stores every part ever removed from any piece of equipment. Some parts have been in the box for years, but nobody dares to throw them away or admit that they don't even know where they came from. The box always has a lot of Velcro in it, and ours had lots of pairs of girls' tights (they were used to hold children in chairs with the help of a dycem mat to sit on). The box never has anything about CE marking in it, and nobody seems to mind...

Using this type of box, Leslie had the imagination and initiative to design a valuable piece of positioning equipment, known today as the i2i head support.



From the box of spare bits to the final product!

Leslie is one of the most inspiring speakers on posture and mobility that I have ever heard: she had many “real life” examples that brought the course to life, and her handout was not just a re-run of the slides. The slides are available on the BES website, but without being delivered by Leslie, they really don't do the course justice.

Although the course assumed prior knowledge of normal development and optimal positioning, less experienced clinicians were welcome, and there was enough content in the day with revision of the principles of good positioning that any attendee should have gone away having learnt plenty.

Leslie shared many of her own clinical experiences, and with excellent videos from her field of work, she showed how optimal positioning of the head impacted on so many daily functions. We tried a couple of experiments individually, and in pairs, to demonstrate how difficult it is to breathe and to swallow with our head and neck position compromised. For us, trying to swallow a cream cracker with our necks fully extended, and heads unsupported, was quite a frightening experience, and it felt as if we could easily choke. But for people in a wheelchair without adequate head support and unable to communicate, how different would this scenario be? It really did make us think how much we take simple tasks for granted every day.

As a clinician who has worked mostly with children, one section of the course that I found particularly useful was entitled "poor head control, or poor sitting?". It made me re-evaluate some of my clinical decision-making with regards to posture and supportive seating.

I think it's so important for a clinician to stand back and reflect on what we have done, why we did it and, more importantly, would we do it again? Once we stop asking those questions, we cease to be putting the client first. This message came across throughout the day.

Leslie talked of the consequences of setting up a chair inappropriately for a client, be it with too much or too little support. She talked of the chain of events that could follow, and she always came back to how these might impact on, or cause, a poor head position. "Like everything else in life, it is often paying attention to detail, and the small simple adjustments, that make the biggest differences in comfort, function, safety, and well

being. That applies to things like proper crutch height, good body mechanics, proper seat depth, and appropriate cushion choice, to name a few." (Fitzsimmons 2009).

Head and neck support should not be an afterthought

At the time of this course I was working for Whizz-kidz, and it dawned on me during the day that it isn't about the amazing chair and all its functions, or about the most comfortable seating system the children have ever sat in. It's about the whole package and, most importantly, if the head and neck are not adequately positioned for comfort, function, vision, swallowing and breathing, then the package isn't really that relevant.

We all need to make sure that the head and neck are not an afterthought. If the manufacturer/supplier you are using for the chair or the seating doesn't have the correct head support you need for your client, don't just compromise. Gather all the information needed before the equipment trial so that, if you think you need to try a more specialist head and neck support, this has been considered and it's available for the assessment.

I would encourage anyone to attend this course; to listen to Leslie was a pleasure, and at no point in the day did it feel like "a sales pitch". She had been involved with the design of a truly great product, and she had the clinical evidence to back up her findings, including videos of children using the i2i demonstrating the difference it made to activities such as eating and vision. This use of before and after videos is a tool we do not use often enough as clinicians; we all need to show how the correct equipment can impact on everyday life and not just on mobility.

"Your clients are looking to you for as much advice and assistance as you can provide them with. It is important to use your knowledge and ingenuity to act as an advocate on their behalf." (Fitzsimmons 2009).

References:

Fitzsimmons, L. Quoted from training day 'Look me in the eye'. June 2009. Birmingham.

**Contact details for Joanne McConnell:
Email: Joanne.McConnell@ottobock.com**

Leslie Fitzsimmons is presenting her latest Look Me in the Eye course as part of the pre-conference Training Day on June 6th 2010.

see page 42 for details

Please ensure that your PMG membership details are up-to-date!

Book Review: "Research Methods for Clinical Therapists: Applied Project Design and Analysis"

Author: Carolyn M. Hicks

Publisher: Churchill Livingstone Elsevier, Edinburgh 2009 ISBN: 0443 07430 5 Price: £37.99

Review by Marie Kelly, Senior Lecturer in Occupational Therapy,
School of Health & Social Care, Oxford Brookes University

Target Audience: Those with minimal or no experience of research methodology

Recommended experience level of reader: This book is aimed at allied health care students, both undergraduate and postgraduate, and those clinicians who may be planning to conduct research or who are interested in developing their research methods skills.

Overview/Summary: This is the latest edition of a well established research text that aims to inform the reader about the design and analysis of experimental studies. It provides wide coverage of all aspects of experimental design relevant to therapists including dissemination and critical evaluation.

The book is an easily understood textbook. It is applicable for use by undergraduates, postgraduates, and by clinicians who are considering doing research or who want to become more critical users of research evidence. It would also be valuable for those responsible for the teaching and delivery of experimental research methods in a health care context.

The book is split into three sections with between six and twelve chapters in each: the first relates to design of research projects, the second to statistical procedures, and the third to some research applications.

Section One, *Research Design and Statistics*, is the largest section. It addresses the knowledge and information required to design, execute and critique experimental research. It provides an overview of types of research design, including the randomised control trial. A small section on basic maths is given which is helpful for readers who may require some revision of basic maths rules and use of statistical symbols. Other topics addressed include: questionnaire and survey methods, sampling methods, the nature of the data, hypothesis testing, and ethical considerations. Features such as blinding procedures, sample size and its calculation, the use of probabilities, significance levels, and Type I and Type II errors are presented. Matching of statistical tests to research design is also described. The final chapters relate to the practicalities of preparing a research proposal, executing the design, writing up for publication (which includes information on preparing poster presentations), and finally the processes to consider when critiquing published research. A completed critique of a research article is included in the appendices and illustrates clearly how knowledge of research methods is applied.

The second section, *Carrying Out Statistical Tests*, describes how to carry out parametric and non parametric statistical tests, as well as providing clear explanations of the techniques of estimation such as point and confidence estimates and their relevance to clinical practice.

The final section, *Research Applications*, provides an overview of some applications that may not be familiar to many therapists. These include items such as *Calculation of Inter-rater Reliability Measures*, the *Receiver Operating Characteristics*, and the *Thurstone Paired Comparison Technique*. These techniques are clearly outlined and can be used to capture user perspectives, expert opinion, or develop attitudinal scales, or diagnostic or screening tools. Clear descriptions are provided of how they may be used in clinical practice, and may inspire readers to evaluate other aspects of health care delivery and satisfaction. Better known methodologies such as Systematic Reviews are also discussed.

The book is written in clear, accessible language, and each section is very well explained. Wide varieties of clinical scenarios are used to illustrate these explanations, and are an important aid to reader comprehension of core research concepts. The consolidation of learning and understanding is further



helped by the use of dialogue boxes at the end of each chapter which summarise the key concepts being discussed. Small exercises and activities listed throughout each chapter help increase knowledge and understanding, and could also be a very useful part of classroom activities.

As the book progresses there is very clear signposting to preceding material to help strengthen the links between research concepts and design features.

The judicious use of explanation throughout the book ensures the reader is not overwhelmed by theory. For those who wish to know more, further recommended reading and up-to-date websites are listed at the end of each chapter.

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Made to Measure – a Review of Two Books:

"A Physiotherapist's Guide to Clinical Measurement"

Authors: John Fox and Richard Day 271pp

Publisher: Churchill Livingstone, 2009 ISBN: 978-0-70203610-1 Price: £16.99

"Joint Range of Motion and Muscle Length Testing 2nd Edition"

Authors: Nancy Berryman Reese and William D Bandy 509pp and DVD

Publisher: Saunders, 2010 ISBN: 978-1-4160-5884-7 Price: £39.99

Review by Barend ter Haar

Measurement is crucial in the initial assessment of an individual, and then as a means to monitor changes over time. The first challenge is how this can be done consistently by an individual, let alone by different people. Many clinical measurements are taken from palpable bony landmarks, but these are seldom distinct spots, and often not readily palpable! The next challenge is how these measures can be recorded consistently and reproducibly. This need was recognised by the production of the International Standard ISO 16840 Wheelchair Seating, Part 1, Definition of Body and Seat Measures.

These two recently published books take the reader through the standard measures that a clinician is likely to be making, but even in their introductions on how to record starting point (zero point), flexion, and extension, they come up with different approaches, recording these in different sequences, thereby emphasising the need for standardisation to facilitate communication. Both books emphasise the need to consider the reliability and validity of measurement tools, but then, when it comes to the chapters on actual measurement instructions, the risks and limitations are not commented on for each measure.

The clinical measurement text (from Churchill's *The*

Physiotherapist's Toolbox series) covers each joint, the spine, and the respiratory system. For each, as appropriate, bony landmarks, ligaments, and muscles involved are listed, followed by range of movement, muscle bulk, muscle strength (Oxford muscle grading), and length measures.

Since the bony landmarks are so important for many of these measures, I was disappointed that in this text both that the copious illustrations did not show where the landmarks were situated, and that the photographs were taken with the models' clothing obscuring many of the landmarks. The authors of the larger book did better here, and used red dots to highlight the position of the landmarks, and their models were dressed so that the landmarks could be seen. This would have been further enhanced in the latter if the pictures showing the use of the goniometers had had the red dots included in them.

Berryman Reese and Bandy's text is a comprehensive textbook covering the areas in the title, namely Range of Motion, and Muscle Length testing. For each body section the techniques to acquire the measures are covered, and followed by a chapter covering apparently pretty well all the research carried out on the reliability and validity of these measures. As mentioned above, the opportunity was missed to introduce the lessons learned

from exhaustive trawls through the literature into the measurement technique chapters.

This textbook is accompanied by a DVD providing video presentations of 120 of the procedures from the text. Showing people dynamically how to do things is a great teaching tool, but the opportunity to make best use of this tool has been missed. For most of the procedures there is a voice over with the model lying stationary. If someone had been pointing out the elements covered by the voice, coloured markers placed on the models, and the swim costumes that are used in the text used on the video models, then users could rely extensively on the short films for instructions on the procedures.

Both books are spiral bound so that they can be laid flat for practical use. Fox and Day's book is a useful summary and reminder for those who have already been taught the required anatomy, and covers a broader range

of measures, including spirometry for respiratory function. The larger book, if read through and through for the area of the body of interest, will give an informed and well-documented overview of the procedures for measuring that part of the anatomy, and the reliability and validity of those measures. Let's hope that by the time of the 3rd edition, more acceptance of standardised measures will be in place, and that the DVD is refilmed to make full use of this medium's potential.

Despite the shortcomings highlighted, both books offer value to the personal libraries of the readers of this journal. More assessment and informed measurement of wheelchair service clientele is needed.

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1st Announcement & Call for Papers

National Training Event

13th to 15th April 2011

Warwick Arts Centre, University of Warwick

We wish to invite you to PMG's next annual NTE, being held again at Warwick Arts Centre, University of Warwick, Coventry

Papers (for platform and/or poster presentation)

The submission form and criteria will be available online from September 2010.

Abstracts for the 2011 event will be published in the conference compendium

Further information on all the above will be notified via the regular ebulletins to PMG members, or contact olwen.ellis@pmguk.co.uk; Tel/Fax: 0845 1301 764.

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Safety of Wheelchair Occupants

Department for Transport Reports

The following reports are available to download from the Department for Transport website:

Safety of Children in Wheelchairs

(Product code 08DFT003)

www.trl.co.uk/news_hub/news/press_releases/detail/Safety_of_children_in_wheelchairs.htm

The Safety of wheelchair occupants in road passenger vehicles

(Product code 02DPL019)

www.dft.gov.uk/transportforyou/access/tipws/thesafetyofwheelchairoccupan6168

To order free hard copies,
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RAatE 2010

Recent Advances in Assistive Technology & Engineering Conference and Exhibition

MONDAY 29 November 2010, At University of Warwick Conference Centre, Coventry, CV4 7AL

RAatE 2010 is the only UK conference focused on the latest innovations and developments in Assistive Technology. This conference will be of interest to everyone who uses, works with, develops or conducts research on Assistive Technologies (AT).

This year's event is run in association with the Health Design and Technology Institute at Coventry University. The HDTI seeks to develop new products and new systems of care provision for the assisted living sector.

The conference program has, over the past years, regularly included new technological developments, service innovations, results of formal research projects, service based research and development and a wide range of other stimulating topics.

Known as a friendly and productive conference, **RAatE** offers you a chance to meet and share knowledge and experience with other people working in AT.

RAatE attracts a multi-professional, multi-agency audience, including:

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- Rehabilitation Engineers, Clinical Technologists and Clinical Scientists
- Teachers, IT Co-ordinators and Disability Officers
- Researchers and Designers
- Suppliers and Manufacturers

RAatE 2010 is now accepting papers for this year's Conference under the following categories:

- Case Studies of Successful Interventions
- AT for Older People / Telecare & Telehealth
- Innovative Access & Innovative Wheelchair Control
- AT in Education

To book your place at **RAatE 2010** register online at www.raate.org.uk
Cost is £125 inclusive of VAT.

For more information on sponsorship opportunities or to book an exhibition stand please contact hdti.info@coventry.ac.uk



TOBY CHURCHILL



The Chailey Approach to Postural Management

Active Design, Birmingham

Course dates in 2010: 16/17 June & 14/15 July (September dates to be confirmed)

This course aims to develop your knowledge and skills of postural management issues for people with cerebral palsy using a biosocial model.

The GMFCS is used to identify risk and need with the Chailey levels of ability. You will learn to describe postural analysis as an effective assessment tool to measure postural ability and prescribe solutions to enable people with postural impairment to function effectively.

The activities during the 2 days are organised to give you opportunities to share your skills and use your clinical reasoning to identify priorities for children and young people at different stages of their lives.

Email: Rachel@activedesign.co.uk Tel: 0121 326 7506



Call for Papers

Advances in Special Seating and Wheelchair Product Design

Wednesday 29 September 2010

Austin Court, Birmingham

*Organised by the IPEM Rehabilitation and Biomechanics Special Interest Group
Co-sponsored by Posture & Mobility Group**

Please submit one-page design briefs and image if available (electronic versions preferred)
by 4 June 2010 to:

Mr Dominic Nolan, Clinical Science & Engineering, Salisbury District Hospital,
Salisbury, SP2 8BJ Tel: 01722 439553 Email: dom@salisburyfes.com

** PMG members book at IPEM member rate*

PRE-CONFERENCE TRAINING DAY**6th June 2010****SECC, Exhibition Way, Glasgow, G3 8YW**

Full day course	Prices
A. <i>Postural Management for People with Cerebral Palsy</i> Jo Jex	£99.00 + VAT
Half-day courses	
1 course	£59.00 + VAT
2 courses	£99.00 + VAT
Morning	
B. <i>Normal Movement Development and Neuroplasticity: Applying Theory in Practice</i> Marion May and Peter Lane	
C. <i>Choosing an Outcome Measure for your Service</i> Rory O'Connor and Mark Schmeler	
D. <i>Muscular Dystrophy – Medical and Surgical Management</i> Damien McCormack and Margaret Phillips	
E. <i>Measurement, Positioning & Mobility Considerations for Bariatric Consumers</i> Stephanie Tanguay and Jane Fontein	
F. <i>Influences on the Seated Position</i> Menno van Etten	
Afternoon	
G. <i>Educational Workshop on Treating Spasticity</i> C W Roy, Alison Barclay, Lynda Williamson & Barry Meadows	
H. <i>A Specialised Equipment Service – This is How it's Done</i> Emlyn Williams	
I. <i>Physiologic Relationship between Posture, Skin and Function</i> Stephanie Tanguay	
J. <i>Practical Wheelchair Skills</i> Roy Wild	
K. <i>Head Positioning: Look Me in the Eye</i> Leslie Fitzsimmons	

For full course descriptions and details about the workshop presenters, see

www.mobility2010.org/workshops.asp

To book for these courses, go to the main conference booking page

www.mobility2010.org/delegate-booking-form.asp

NB Cirque de Soleil is on at the SECC, 2nd to 6th June 2010.

Details on the [SECC website](#).

posture and
wheeled mobility
2010

**The 4th International
Interdisciplinary Conference
on Posture and Wheeled Mobility**

SECC, Glasgow 7 – 9 June 2010

www.mobility2010.org

Provisional Programme

Monday

Plenary Sessions (morning)

Not so easy riders: reflections on achieving wheeled mobility – *Tom Shakespeare*

The importance of keeping your dignity – *Anna Geirsdottir*

Performance Arts – *Marc Brew and Caroline Bowditch*

Outcome Measures: what can I use in my clinic? – *Rory O'Connor and Mark Schmeler*

Parallel Sessions (afternoon)

Best Practice Guidelines:

Power wheelchairs for paediatric users – *Josephine Durkin*

Early Interventions – best practice before the patient reaches the rehabilitation unit – *Laura Graham*

Vehicular transportation for users occupying their wheelchairs – *John Tiernan*

Workshops

Upper Limb/SCI

Physical Assessment – A “how to” guide for engineers, nurses and therapists – *Jean Minkel and Dorte Stovring*

Technical Workshop – Changes in properties with use: aged to perfection or it's downhill from here – *Evan Call*

The MDD – How does it apply to my every day practice? – *Peter Diesing*

Free Papers

Measurement Stream

Upper Limb Stream

Tuesday

Plenary Sessions (morning)

Tissue Integrity and Support Surfaces, Where We Are... Where Should We Go?

- Wounds and their causes
- EPUAP/NPUAP pressure ulcer treatment and prevention guidelines
- Testing Support Surfaces

Community Rehabilitation – *Chris Ward*

The ethics of decision-making for people with disability – *Andrew Hanrahan*

Capacity and cognition – *Alan Carson*

Parallel Sessions (afternoon)

Best Practice Guidelines:

Preservation of Upper Limb Function following spinal cord injury – *Tina Roesler*

Clinical Practice Guidelines: Transfer Training for Transferring in the Home and Beyond – Part 1 – *Jean Minkel*

Seat Elevating Devices for wheelchair users – *Lise Møldrup*

Tilt, recline and elevating leg rests for wheelchairs – *Helle Dreier*

Workshops

Remote Wheelchair Provision

BSRM Vocational Rehab Special Interest Group – *Judith Allanson*

BSRM Special Interest Group Electronic Assistive Technology

Tissue Integrity

Communication – *Chris Ward*

Free Papers

Assessment and Wheelchair Stream

Product Design Stream

Wednesday

Plenary Sessions (afternoon)

Opportunities for joint working: holding hands with industry

Collaboration in Toronto – *Geoff Fernie*

Programme for prevention of hip dislocation and severe contractures in cerebral palsy – *Gunnar Hagglund*

Medical problems affecting posture and movement – *Margaret Phillips*

The role of medicine in promoting function in posture and movement – *Andrew Frank*

Parallel Sessions (morning)

Best Practice Guidelines:

Empowering Children and Adults with cognitive disabilities to learn skills for powered mobility – *Rosalie Wang*

Supported Lying – *Joyce McDonald*

Clinical Guidance on use of pressure mapping systems – *Pat Meeker*

Clinical Practice Guidelines: Transfer Training for Transferring in the Home and Beyond – Part 2 – *Jean Minkel*

Workshops

Invasive Management for Spasticity – *Chris Roy*

Fundamentals of Research – *David Porter and Marie Kelly*

Trouble Shooting: Enabling Active Wheelchair Use – *Hannah Proctor, Lone Rose*

BSRM Special Interest Group Amputee Medicine

Free Papers

Management Stream

Carers and Users Stream

Programme information will be updated on the web site www.mobility2010.org

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- Rehab engineers
- Research workers
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Early Bird Registration Deadline – 9th April 2010

To register visit the web site www.mobility2010.org

See provisional programme overleaf



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