

Best Practice

Consensus, Risk & Evidence

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ABSTRACTS

**DEMANDS FOR EVIDENCE – ARE THEY A ‘SUPPORT’ OR A
‘RESTRAINT’ FOR SERVICE DELIVERY?**

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Clinical governance, NICE, horizon scanning, clinical pathways and numerous other recent initiatives have created a new culture in health care provision and practices where interventions are expected to be supported by research evidence. Medical technology has long been seen to be a cost inflator for health care services. New advances attract significant public interest, often promise improved outcomes or less invasive procedures - but with a price tag. To add to the pressure, NHS has tended to lag many other developed countries in adopting new medical technology advances due to these cost pressures. Healthcare systems in most developed countries are requiring companies developing these technologies to provide cost-benefit-effectiveness studies before they are adopted. There are many issues that have to be considered, not least ensuring that such studies are conducted in a scientifically robust and independent manner. The cost of such studies can be high and their design complex. Not infrequently ethical problems arise in randomly allocating patients to “control” technologies that are by all appearances less sophisticated to make comparisons with the new development.

Assistive technologies are not immune from these pressures for evidence and in many respects encounter greater challenges. Unlike pharmaceuticals it is not possible to conduct meaningful randomised clinical trials for most assistive technologies. Selecting subjects for studies and stratifying them is complex given the multiplicity of clinical and sociological factors associated with disability. The cost of these trials can be prohibitive for the small to medium sized enterprises responsible for manufacturing the vast majority of assistive technologies. Yet very little government funding is set aside to systematically evaluate these virtually “orphan” technologies. Ironically where larger companies have evolved (wheelchairs provide an example) some negative influences of globalisation are apparent. These predominantly US based companies have very small European R&D budgets and often funding for systematic trials is centred at USA facilities. The particular needs, specifications and cost-benefit issues of UK users is therefore not effectively addressed by manufacturer sponsored trials.

In this presentation we will discuss how expectations for evidence based practice in the provision of assistive technologies need to be managed to ensure that we do not smother the opportunities that new technologies offer people with disabilities. We will also investigate some effective strategies for generating evidence such as “smart devices”, technology templates and alternative funding methods.

MEXICAN EXPERIENCE

Sarah Davies, Occupational Therapist, Hampshire

Here is a brief description of my experience in Mexico. I was working in an unpaid capacity in an institute for children with cerebral palsy called 'Instituto Nuevo Amanecer' (which means 'new dawn'). It is an amazing and admirable institute, funded totally by charitable donations, providing medical care, rehabilitation and education for a large number of children. The catchment area is vast, Monterrey has a population of 3.5 million.

Most of the children require a wheelchair, many have none at all and the ones that do are seated in very dilapidated and unsuitable seats. When I arrived, there was no knowledge or expertise in the field of special seating, worse still, there are no wheelchair manufacturers, no special seating equipment available and huge problems importing equipment from the US. (Even if there had been enough money!)

The staff in the institute were very keen to use the expertise that I was able to give them. Together we built up a team of doctors and therapists who are now familiar with the methods of postural management which we use here in the UK and are trying to put them into practice.

We developed ways of making seats from locally available materials at very low cost. Initially we experimented in my garage (my husband is an engineer and helped enormously), but later, located a small company to make the seats we had developed including moulded seats, modular seats and a symmetrical seat for babies and young children.

I consulted many companies and individuals on visits home who were extremely generous with advice, expertise and samples of equipment to copy. Chailey Heritage, in particular, allowed us to translate their excellent book 'The Chailey Approach to Postural Management', which we used as the basis for the training courses I ran for all the staff. This meant that the seating clinics, which I started as soon as I arrived, became real postural management clinics, with the emphasis on the 24-hour approach.

We found ways of upholstering the moulded seats, making lap straps and harnesses, headrests, simple adjustable wooden standing frames, corner seats and equipment for positioning in bed, but we did not solve all the problems. We raised money to build and equip a workshop and pay the salary of a technician to work in it, fixing and adapting the wheelchairs that we had available to us.

The institute does a tremendous job with few resources, huge financial constraints and very little quality training for their staff. They are taking the postural management programme into the wider community to share their knowledge and skills in this field. There is still an enormous amount to do. Training is needed, not only in the field of posture and mobility, but in many other areas. I am committed to help them, in whatever way I can, but particularly to obtain better training. This could be here or, better still, finding experts willing to go out and work with them for short periods. Not least, I need to overcome the problem of obtaining decent wheelchairs. I shall be at the conference and look forward to meeting anyone who is interested in talking to me about this project.

**MAPPED, BENCHMARKED, 'POOLED' AND ANALYSED EVIDENCE FOR
CHOOSING, EVALUATING, COSTING AND INNOVATING
WHEELCHAIRS AND SERVICES**

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Background, Aims, methods and progress: This presentation reports the latest stage in an R&D development with the overall aim of generating consumer evidence to empower stakeholders to restore autonomy effectively and economically.

Methods: An investigation of wheelchair development and supply for the Nuffield Provincial Hospitals Trust (Mitchell, 1977 and 1985) revealed the need for systematic evidence of consumers' needs. Subsequent work investigated consumers' priorities and problems (Ohras, 1997), developed the Wheelchair Lifemap as a holistic, consumer-centred assessment tool (Mitchell, 1998a) analysed the processes of choice and innovation for the NHSE. This work was further developed for the King's Fund (Mitchell, 1998b and Bennington, 2001) and Lifemap user-trials were undertaken for the DoH (Mitchell, 2000). The initial West Midlands pilot will be funded by the Sandwell Health Trust. This aims to find out how benchmarked evidence affects stakeholders' practices and strategies and also, how to build individual evidence into a strategic 'consumer evidence base' for planners, providers and policy-makers.

The need for evidence: Consumers, innovators, manufacturers, providers, retailers, the voluntary sector, planners and policy-makers must use their resources well if they are to restore autonomy to dependent consumers. Each needs evidence about consumers' priorities and problems to target their responses effectively (see references cited).

Obtaining the evidence: The use of paper for records and limitations in both IT and assessment technology have so far prevented this evidence from being effectively collected and used (Mitchell, 199a, b, 2000, Bennington, 2001), 8). However, recent advances in assessment technology (Veloza, 1999, Kielhofner, 1993 and 1995, Law, 1994 and Sanderson, 2000) and hard and software may soon provide stakeholders will an upgraded, integrated evidence-system (Mitchell, in press) for revealing and responding to their consumers' needs. Such a system should:

- 1 'Map' consumers' individual lives and priorities
- 2 'Benchmark' their existing dependence to measure subsequent changes and to provide clear starting point for choosing, evaluating, costing and innovating present and future responses
- 3 'Pool' and analyse individual benchmarks to provide strategic evidence on dependence, its prevailing patterns, their causes, their responsiveness to different interventions and areas where improvement and innovation are needed

Mitchell et al, 2000, Testing the Wheelchair Lifemap, Ricability, London
Bennington et al, 2001. Autonomy for disabled people – mutual problems, mutual solutions, The King's Fund, London

THE DEVELOPMENT OF A NATIONAL CLINICAL DATABASE OF WHEELCHAIR USERS

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The population of wheelchair users in England exceeds 500,000 in size and includes a large proportion of the population with significant mobility restriction. The number of issues of new wheelchairs has exceeded 100,000 annually for several years. In health care terms, the population is large and the activity and resource consumption considerable. Clinical service provision and management require that an effective information structure is established and maintained. Whilst this permits analysis of clinical information on a local basis, it is impossible to provide any clinical analysis of national wheelchair issues. (The Purchasing and Supplies Agency can provide a national analysis of commercial activity only for wheelchairs.)

Wheelchair provision and the associated activities are administered through 160 centres. The needs of service management and clinical governance require that some form of local database is maintained. This varies in complexity from paper based minimal data structures to complex multi-centre electronic databases. There has been no central collation of data since the devolution of wheelchair services to local levels by the Disablement services Authority; this probably explains why there is no national data structure in existence. A rather similar situation occurred in the field of amputee care but a national incidence based clinical database has been established and reports are produced annually (the National Statistical Amputee Database).

A national database of wheelchair clinical and managerial activities will fulfil a number of important service needs. In particular, it will become the data framework from which many of the actions required by clinical governance can arise. For the first time, issues of equity and access will become transparent. Short and long term clinical and managerial research will become possible. Service planning can be undertaken with a rational underpinning for both local and national requirements. Commissioning initiatives can be designed and developed on a firm factual basis. There is thus a clear need for a re-iterative national clinical database describing the wheelchair user population.

The diversity of data systems already in use make it unlikely that a truly national database for the wheelchair using population can be achieved (cf. the amputee database which captures more than 95% of the incidence data). A representative number of wheelchair services (15 of 160) use the Redwheel database; the data sets are current, well populated and accurate. A pilot study has been conducted in which a sample database comprising 10% of the wheelchair user population of England has been constructed. The data set has been devised in draft form with the assistance of the Redwheel User Group and illustrative data extracts will be presented.

The authors, who comprise the ad hoc working party for the project, welcome feedback about the future of the project. Discussions about funding are under way; future resources should allow the inclusion of data from other database engines into a national database thus representing a larger sample of the wheelchair user population.

The authors are grateful for the support and advice of the Redwheel User Group in the development of this project.

DYNAMIC PRODUCT DEVELOPMENT OF THE CAREVA HARNESS SYSTEM**Evastina Björk**

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During my work with rehabilitation for disabled children and young people with spinal cord injuries in Sweden as a professional Occupational Therapist I discovered the need for safe and comfortable mobility. There was at that time (1983) no equipment available for those people who needed posture support in vehicles. The ordinary safety belt systems in vehicles could not provide enough support, therefore the support was provided by some personal assistant or by some kind of rope or belt which was draped around the person in the same way as luggage is fastened. This was of course a very unsatisfactory solution for the problem and thoughts of developing a harness system for disabled children started to grow in my mind. It took several years before the thoughts and the intention became reality.

The development of a harness system for disabled children started in 1995 in the company Careva Systems and with a methodology called DPD Dynamic Product Development (Ottosson 1995). This product development concept was based on user involvement in combination with a relatively small project organisation. The project was documented as a case study and was presented at Chalmers University of Technology in Gothenburg, Sweden in June 1999 as a thesis for licentiate grade in technical engineering.

The creation of ideas and the stages of making models and prototypes were carried out in very close contact with disabled users in their various contexts, which made immediate testing of prototypes possible. This cooperation gave feedback to the project very quickly and the development of new and redesigned solutions were tested continuously during the project. After one year the project presented a harness system which we knew was flexible and which covered most of the demands that users and their relatives had given to us when the project started. The system was also tested by VTI, the Swedish Council for Road & Traffic Safety. Today, four years later the Careva Harness System is a well known harness system in Scandinavia for use in vehicles including Community Transport as well as in wheelchairs. Details in the system have been redesigned and will continue to be so in the future to ensure good usability.

THE DEVELOPMENT OF PROJECT SERVICES IN THE WEST MIDLANDS REGION

**K. Jarvis, OT, Chair of the West Midlands Wheelchair Service Managers Group,
D. Harrison, RE Manager, West Midlands Rehabilitation Centre, Birmingham**

In 1999, the 16 wheelchair services in the West Midlands recognised that there were significant benefits to co-operating and co-ordinating service developments and special projects on a region wide basis.

All the services agreed to allocate resources to collectively commission the Regional Centre to provide a project service, which would be owned and directed by the District Services, using the Centre to co-ordinate the process. This model is a logical development of commissioning RE Services from the Regional Centre.

The project service aims to develop and promote best practice in all areas of wheelchair and special seating provision. It includes the evaluation of new products for possible inclusion/replacement in the regional product range and establishing common procedures for key areas of service provision.

Service level agreements were developed between the District Wheelchair Services and the Regional Centre equating to a WTE RE. A Rehabilitation / Project Engineer was recruited for the post.

Project ideas are accepted from any service manager, with the group agreeing priorities. Project progress is tabled at bi-monthly meetings, with the opportunity for managers to re-prioritise schemes. User groups are also informed of project progress and can request via discussion with their District, consideration of projects which the manager will present.

Projects are managed and allocated to appropriate staff by the Regional Centre. If Districts have a particular interest in leading the project, staffing to cover to the District is provided to allow their member of staff to participate.

A project "evidence file" is opened to house all information gathered / produced, with a summary report issued to each District Wheelchair Service Manager. Other interested parties, e.g. manufacturers are encouraged to view the reports produced.

Projects commissioned to date include methods of data tagging wheelchairs, guidelines for clinical risk assessment, recommendations for transportation of wheelchair users and their wheelchairs, regional co-ordination of reporting Adverse Incidents, appropriate goods Inwards inspections including rejection criteria and numerous wheelchair evaluations which always involve obtaining user feedback.

Ongoing Projects include improved hardware and procedures for Stability Testing Wheelchairs, a cost effective "Foam Fit" seating system, evaluating a 8Lstyle replacement and evaluating manual "tilt in space" comfort wheelchairs.

Future planned projects include, Guidelines on wheelchair Inspection (In house / Repair service), a User controlled power pack and a comparison between current Children's EPIOCS.

The Project Service has enhanced collaboration between the Wheelchair Services within the West Midlands. A formalised, rigorous approach to equipment evaluation had been an aspiration of most Districts for a number of years. However, with increased workload commitments this could not realistically be achieved in each individual District, and so the pooling of resources has benefited all Districts and ultimately users in the Region.

FAST RESPONSE SERVICE**D. Harrison, RE, S. Rampton, OT**

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The Regional Posture and Mobility Service and the Regional Wheelchair Trading Service at the West Midlands Rehabilitation Centre have combined resources to provide a "Fast Response Service" to In-patient facilities within the region. For practical reasons these have been limited to local Birmingham hospitals and the Midlands Centre for Spinal Injuries, Oswestry. The service is aimed at clients who have no current mobility/seating and are in the early stage of rehabilitation following injury or illness.

The service aims to ensure that the client's rehabilitation is not compromised, through lack of an appropriate wheelchair seating system. The focus is on loaning equipment for a relatively short length of time, particularly in cases where the speed and extent of recovery of the client may be unknown.

The equipment is drawn from a stock of seating systems ranging from Bencraft Pioneers to comfort wheelchair seating systems. Similar models of equipment, once returned, are salvaged for spare parts, to maintain the fleet. All equipment is decontaminated, serviced, inspected and recorded into an equipment catalogue, before a loan takes place.

The service process is :

- Referrals are received from Health Care Professionals directly to the Posture and Mobility Service Co-ordinator
- Team prioritise the referral,
- Visit arranged - if possible, suitable equipment identified.
- OT and RE assess the client. Explanation that long-term seating needs remain the responsibility of the District Wheelchair Service.
- Suitable equipment is supplied within 2 weeks of the referral being made.
- Sitting programs are devised with therapy staff and client (if appropriate).
- Regular reviews are carried out, and recommendations are then made to the District Wheelchair Services for long term provision.

Purchase of wheelchairs and seating is costly for the District Wheelchair Service, and in some cases specialist seating may only be required for a limited period of time. A variety of different types of seating may be required throughout the rehabilitation process and a client may become less dependent on specialist equipment. The Fast Response Service attempts to address the gap in the service between lack of ward mobility/seating and long term District Wheelchair Service provision.

An overall view of the service will be presented, together with a single Case Study. Within the Case Study the following will be discussed:

- Spontaneous recovery
- Spasticity management
- Reduction of deformity
- Promotion of function and normal movement.

Whilst in its infancy, the Fast Response Service has made a promising start.

CAREGIVER TRAINING PROMOTING OPTIMUM USE OF POSTURAL SEATING SYSTEMS

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Postural seating enables people with abnormal neurological pathology or skeletal deformity to attain seating posture. Misuse can result in pressure sores, secondary deformity development, and dysfunction. Occupational Therapists (OTs) have a duty when recommending, issuing, or following through the equipment recommendations, to instruct and nurture correct usage.

The aim of this study, conducted in 1998 was to survey current caregiver training practices undertaken by OTs in the field, to promote optimum postural seating system usage. Search for literature on caregiver training in postural seating system usage revealed no previous research on the topic at the time. Two hundred and fifty randomly selected attendees, of two specific posture and posture management courses during 1995-1997, were invited to take part. Of the 85 OTs who responded 61 consented, and were sent self-administered postal questionnaires. Forty-seven questionnaires were returned appropriately completed. The majority, at 73% were NHS/NHS Trust employees. Sixty-four percent practiced as specialists. Relevant experience in the field averaged at 5 years. Seventy-nine percent of participants were involved at least monthly, with clients prescribed postural seating systems.

Although no significant findings were made, the study discovered that participants provided caregivers with practical skills training in equipment usage, more than knowledge-building opportunities. Intervention usually occurred on an individual basis. Participants' services tended to operate reactively to problems occurring. The study suggested that caregiver training groups based on psychoeducational and (androgogic) adult learning may reduce problem incidents, enabling further development of timely, pro-active practices such as regular systematic reviews.

Based on the study findings, the author devised and initially implemented a training package for care-staff of Jersey's Adult Learning Difficulties services. This included nursing staff and auxiliaries of hospital wards and group homes, adult day centre staff, and Mencap staff who provide group home and respite opportunities. The focus of the training was to enable and empower care staff to improve their ability to place and position clients in their postural seating systems, thereby well maintaining client's postures.

Clinical audit in 2001 of the training package given to 68 care-staff provided evidence of satisfaction and efficacy of this style of training. Twenty-one randomly selected recipients participated in a multiple-choice questionnaire designed to probe their knowledge/ information retention of information. Their therapists, through direct observation of clients' posture and positioning, gauged practical application of this acquired knowledge. Good sitting posture with adequate levels of support were observed in 11/12 clients.

Ultimately the aim is to broaden availability of this training to other States Health and Social Services Departments, through transcribing this training package into National Vocational Qualification (NVQ) Level 2 in Care. To succeed, the support of Operational Managers across all relevant departments must be solicited, so that they will promote and formalise incorporation of the training into their staffs' inductions and continuous staff development plans.

GOOD SITTING ... NOW WHAT CAN YOU DO?

Liz Scott-Tatum

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Aim of session: to reflect the findings from a study that sought to identify the functional gains associated with the use of Dynamic Lycra Splinting. The findings presented are those associated with one of the functional sub-groups, which explored the impact on sitting ability.

The study took the structure of a within subject design, and employed a series of qualitative and quantitative measurements. I will present the changes in each of the areas tested; the measurement tools used including:

- Chailey Sitting Ability Scale
- OPCS disability scale
- Canadian Occupational Performance Measure
- Modified Ashworth and Tardieu scales
- Diary Text
- Questionnaire text

Information related to postural management, pharmacological interventions and therapy input were recorded at each measurement interval, as it is recognised that these are potential variables.

Results: The general trend for the sitting posture group (n=6), suggests that there is a positive effect from the use of dynamic lycra splinting (Up-suits), on sitting ability, gains being seen in 5 of the 6 individuals completing the project. The sixth group member remained at the same level of sitting ability through out the study.

Inferential analysis of the findings , with and without the splint over a six month timescale, will be presented.

Conclusion: I will demonstrate that there is a significant impact on sitting posture through the use of dynamic lycra splinting, which may be of a significant benefit to individuals presenting with a range of tonal disorders: athetosis, hypertonia, hypotonia, and possibly dystonia. Providing individuals with greater central control, enables the potential for distal function and head control to be optimised. It is recognised that the subject group is small, and that care should be taken in generalising the findings of this study.

References:

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**WHIZZ-KIDZ / DEPARTMENT OF HEALTH WHEELCHAIR TRAINING
PROJECT- EXPERIENCES OF TRAINING – A WHEELCHAIR SERVICE'S
PERSPECTIVE**

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Introduction: Research has shown that disabled children and young people are less likely to have active social lives, to take part in out of school activities, clubs or sports, and are more likely to stay within the home environment. This lack of participation in community life has been linked to disabled young people's lower levels of self esteem and poor self concept (Hirst & Baldwin, 1994). Wheelchair skills training is one way to help young wheelchair users make safe journeys from the home, to develop their confidence to use their equipment in a greater variety of settings and to increase their social interactions and autonomy.

The opportunity has arisen for Whizz-Kidz to pilot a national standardised training programme in wheelchair mobility skills for children and young people, having been awarded a Section 64 grant from the Department of Health. The first priority has been to establish what training is already provided and, therefore, a wheelchair services survey was carried out in October 2001.

Study Aims and Methods: The aim of the survey was to establish the extent of training provision available for children and young people and to clarify wheelchair services' needs and experiences throughout the UK. A self-completion questionnaire was sent out to all 168 wheelchair services, with a response rate of just over 40%.

Results: The data collected has shown a huge diversity of provision. Almost every service offers some kind of training, but those that offer a structured scheme display a significant difference in their perception of the benefits and difficulties than those that do not. The results have also raised interesting issues regarding who should actually provide this service. The majority, approximately 90%, of respondents agree that wheelchair training is extremely important for children and young people, but many raise questions of funding, staffing and time.

The presentation will look at the implication of this research on wheelchair service practice and responsibilities and suggest possible ways forward, including the increased use of volunteers, the involvement of skilled wheelchair users and the impact of the new Whizz-Kidz training package.

References

Hirst M & Baldwin S (1994). Unequal opportunities, growing up disabled. HMSO; London.

**REFLECTIONS ON THE AUDIT COMMISSION STUDY – FULLY
EQUIPPED**

N Mapstone

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

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

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

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

THE SCOTTISH BENCHMARKING PROJECT

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The Rehabilitation Technology Information Service project was established in 2000 to gather information on activity and performance of the four main Rehabilitation Technology services in Scotland. These include Prosthetics, Orthotics, Wheelchairs & Seating and Electronic Assistive Technology. The purpose of the project is to stimulate improvements in these services by providing national information on these services along with benchmarks of good practice against which service providers can assess their own performance. It will also provide information to service commissioners to enable them to make more informed contracts with their individual services. To date, the wheelchair element of the project has collected preliminary 'aggregated' data from all Scottish centres and is in the process of conducting pilot trials for the collection of 'individualised' data. Already, this information is affecting attitudes of commissioners.

This presentation will give an overview of the project and summarise progress to date.

**LINKING SERVICE PROVISION FOR 24 HOUR POSTURAL
MANAGEMENT**

Lisa Jane Tennant BA BSc SROT

This presentation assumes that recipients are aware of the definitions, nature and principles of Posture Management as a 24 hour approach. The main emphasis of the discussion is around the considerations for implementation of such an approach and suggestions as to how to link services more effectively in the future. The speaker is an Occupational Therapist and over the past 10 months has been employed within Portsmouth OT service to research the remit for the most practical and relevant means of delivery of a Posture Management Service for Adults. A very brief description of Portsmouth and South East Hampshire Services will help to provide delegates with some background, particularly in light of the current restructuring of services into three Primary Care Trusts and the implications of this. There is recognition by the speaker that the presentation describes a potential 'model' and this is by no means prescriptive, it is intended to offer one example of how an area is attempting to deliver a Posture Management service. This is driven by the belief that 'action speaks louder than words' and that services must begin to develop initiatives, test out potential models for service delivery and modify and change accordingly, rather than focus too much time on the textbook and discussion phase!. The speaker will describe her role as Project Worker for Posture Management and how insight and useful findings have been gained working with Occupational Therapists, District Nurses, Physiotherapists, Clients and carers, within hospitals and within the community as to the vast scale of the problem. The main considerations for setting up and delivery of such a service include; How to implement such a service?, Who is responsible for implementation? How to Co-ordinate? Who is responsible for co-ordination? How to fund and who will fund for such a service? How to train and Who to train? How to access specialist equipment options? Who is responsible for ongoing follow-up of advice/equipment options? The discussion will close around some suggestions for better linking of services through use of a Specialist Advisory Post.

ESTABLISHING CORE COMPETENCIES FOR ASSESSMENT

R Hodgkinson, H Lumley, W Murphy, P Richardson,

Within this session, Ray Hodgkinson will:

Review the BHTA role and its Registration Scheme – how it has stimulated work on competencies in the commercial sector

Emphasise the unique relationship between the industry and the profession, and the need to match professionals' competencies

Describe the three levels of BHTA's scheme and the core competencies identified

Describe the more detailed work that has started – and how company competencies may differ from the public sector

Explain the need for establishment of new/expanded courses and where these might be provided

The other participants will add the perspective of what is needed in the clinical marketplace.

For example, Wendy Murphy will be covering Posture Management and Provision of Equipment for People with Severe Postural Deficit – Knowledge and Skills:

For many reasons, the number of people who have complex, profound disability is rising. Many people with severe impairment are, or become, non-ambulant with significant posture deficit.

It is vitally important to address the posture needs of the client, including seating for mobility and static seating. Attempting to resolve the problems presented requires a depth of appropriate experience, knowledge and skill.

Inappropriate posture management can lead to secondary problems, which may include deformity, tissue damage and pain, whilst appropriate management can facilitate mobility and function and enhance comfort.

This 15 minute part of the workshop will present the type of client to be discussed. A series of questions will be set, to illustrate the knowledge and skills needed by health professionals who are involved in the provision of equipment.

ASSESSMENT PROTOCOLS

**B ter Haar BES Rehab Ltd
A Moore Gerald Simonds Ltd
C Turner Invacare UK Ltd**

A couple of years ago the BHTA requested Christine Turner to set up a working party to design a simple assessment protocol that could be used universally to assess clients for seating and wheelchairs. The working party has come up with a protocol which has selected best practice from a large number of centres, and incorporated the recommendations for assessing people and their seats in wheelchairs coming out of the new ISO seating standard drafts.

This workshop will be explaining the resultant protocols, and trying to test them out. An outcome of the afternoon will be to try to establish which elements should be used at a basic level, and which elements at an advanced level. Similar exercises are being carried out with the same draft protocol in the USA, Sweden, and Japan.

BENCHMARKING

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This workshop follows the plenary paper on Benchmarking and will give further detail on the Rehabilitation Technology Information project to gather data and establish benchmarks for Wheelchair & Seating services in Scotland. Other similar work will be summarised.

Through group discussion, participants will then be invited to identify their perceptions of the most important characteristics of a wheelchair service and set benchmark targets for the service to achieve from the perspective of the user, the provider and the commissioner.

EQUIPMENT PROVISION: THE REASONING PROCESS**Dr Claire Ballinger**

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An integral part of the occupational therapists' role in working with people with disabilities is to facilitate their optimum functioning in all areas of daily life, often through the provision of equipment. However, the recent Audit Commission Report (2000), 'Fully Equipped' highlighted a number of shortcomings in relation to current service provision, including poorly planned services and underfunding. Studies have reported a mixed picture with regard to continued equipment use, and these issues must be set in the context of an increasingly complex legal framework addressing risk and safety within which practitioners work. This paper therefore has the following aims:

- To provide an explanatory framework with which to understand the reasoning process for equipment provision
- To examine the evidence relating to each component of the framework which might assist in the decision making process

The proposed framework of 'Person-Equipment-Environment' is based on a model proposed by Rogers and Holm (1992). The framework not only encourages a broad perspective with regard to the provision of equipment, but also illustrates how each of the components are inter-related.

The paper will consider elements relating to the individual service user, including functional abilities and preferences, demographic information and psychosocial factors. Literature on adherence will also be considered within this context. Factors relating to equipment will also be addressed, including the importance of the assessment process, effectiveness, appearance and safety. Some of the issues relating to equipment will be illustrated through a study focusing on user and technical evaluations of commodes (Ballinger et al 1995). Finally some of the issues relating to the environment within which the equipment is to be used will be discussed, focusing on architectural characteristics, compatibility, impact on family members and assistance to care givers.

The paper concludes by promoting the occupational therapy literature as a growing resource for those involved in equipment provision, and emphasising the importance of the active involvement of the service user in all elements of equipment design and provision.

REFERENCES

- Ballinger C, Pickering RM, Bannister S, Gore S and McLellan DL (1995) 'Evaluating equipment for people with disabilities: user and technical perspectives on basic commodes' *Clinical Rehabilitation* 9, 157-166.
- Rogers JC and Holm MB (1992) 'Assistive technology device use in patients with rheumatic disease: a literature review' *American Journal of Occupational Therapy* 46, 120-127.

PROVISION FOR CHILDREN

Facilitator: Ros Ham

Director of Children's Services, Whizz-Kidz

Although children and young people only account for approximately 6-8% of the client numbers in a typical NHS wheelchair service database, the amount of both staff time and money spent on this group is large. This is for a number of factors including the few listed below;

- growth,
- developmental factors,
- ageing of both the children and parents/carers,
- changing needs with regard to schools, parental requirements,
- age-related social needs, attitudes, self-esteem and peer pressure,
- inter-related factors such as computer interface at school, communication equipment, environmental control items,
- transportation variation,
- acceptance of disability and stabilisation of the condition,
- interagency working – staff numbers involved and the agencies,
- age and size related equipment currently available in the UK,
- lack of recognition and funding of the equipment requirements,
- funding needs for a variety of sources.

The numbers of disabled children in the UK is known to be increasing, though there is currently no accurate data of either the numbers or the percentage of this annual growth. The problems currently faced by the providers of equipment to disabled children and young people will therefore 'not go away' but will increase.

The workshop will explore a variety of issues that affect equipment service providers to day including the following;

- Published literature – the evidence
- Legislation affecting children today
- Reports about the issues in equipment provision
- User requirements, opinions and meeting need
- Recent Government initiatives and management structures
- Inter-professional and group working
- Funding
- Inter-agency working & funding (NHS Plan 2000)
- Equipment and the costs

The aim of the workshop is to explore the evidence and the facts, the current issues relating to provision and the UK specifically, and to sum up with a consensus view of the way forward for disabled children and young people for the planners for the future.

ESTABLISHING CLINICAL OUTCOME MEASURES

A Frank, M Ferguson-Pell, M Kelly, L Marks

This workshop will look at some of the clinical outcome measures already available, and will be assisted by short presentations from some people who have experience of either a specific measure(s), or its(their) use in practice. We aim to stimulate a lively inter-active debate on how to progress towards routine measurement of outcomes in wheelchair services. Please come and share you views and join in the party !!

Speakers include:

Andrew Frank; " Attempted use of a modified EuroQol questionnaire to assess quality of life in EPIOC users ".

Martin Ferguson-Pell; " Practical experience with two outcome measures during the SCAMP project ".

Marie Kelly; "The Canadian Occupational Performance Measure. How useful is it in an assistive technology setting ?? ".

Linda Marks; " Can we use objectives as a measure of outcomes ? "

AND contributions from the audience.

ISSUES RELATING TO EPIOC PROVISION AND MAINTENANCE

M Belcher, G Blackman, AO Frank, D House, M Pugh and J Ward

Stanmore DSC and Kings College Hospital

This session will be devoted to consideration of the risks of the provision of EPIOCs.

The 3 areas we are able to consider are: -

Engineering issues

- Chair performance (repairs, reliability)
- Life expectancy (whole life cost)
- Control box programming / recording
- Adverse incident reporting (role of AR)
- Design issues (manufacturers)

User reviews

- Needed?
- Frequency?
- By whom?
- Where – clinic or home?
- Posture, driving skills, chair?

Risks of transportation

Chair prescribed (?headrest)

WTORS – type, installation, application

Driving

Vehicle

- Type
- Access (ramps, lifts)

This will enable us to split up into up to 3 groups to cover these issues if numbers are too great for 1 group

What is the way forward for EPIOC services?

EVIDENCE BASED HEALTHCARE – HOW IS IT GOING SO FAR?

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Policy makers and purchasers require health care providers to demonstrate the efficacy of their services, hitherto regarded as self evident. To this end, since the early 1990's, Health Care Professionals (HCP's) have been told that they must seek to use the best available evidence to inform their practice. Bithell (2000).

During the last decade various strategies have been used to promote the use of evidence to inform clinical decision making. However, the question remains, "Do HCP's have the skills and/or the incentive to find, evaluate and apply evidence to contribute to clinical effectiveness?".

This paper will seek to explore the challenges, problems and pitfalls associated with converting the evidence-based paradigm from theory into practice.

Difficulties considered inherent to the problem will be discussed and strategies to overcome them suggested.

Finally, a practical and realistic proposal for action will be outlined.

Reference

Bithell C (2000), Evidence-based physiotherapy: Some thoughts on best evidence. Physiotherapy. 86,2,58-60

THE CLINICAL VALUE OF DYNAMIC SEATING

Bart Van der Heyden, PT

European Training and Education Manager, The ROHO Group

Wheelchair seating interventions are often seen as isolated interventions although they have a great impact on the seated person. By analysing compensatory postures during seating activities we can often see how the seated person is dealing with lack of functional postural support (due to their diagnosis or seating solution). One of the keys to functional dynamic seating is to understand why the person sits the way he does and what he's trying to accomplish when seated in a particular posture during a certain activity. Often there are involuntary and complex compensatory mechanisms present that will enable the person to sit in a carefully balanced way, compensating and compromising between a limited seating balance, tone, Range of Movement (ROM) of key joints and mental condition. Different positions and dynamic seating interventions will be analyzed and discussed during this presentation.

MORE ON DRUGS: QUESTIONS AND ANSWERS

**E Green
R Luff**

This is a follow-on session from the Drugs: Old and New at last year's PMG conference. Participants brought a wide range of questions, many of which were not answered due to time constraints.

This year Robin Luff and Elizabeth Green will attempt to answer further questions from the participants - advance warning if possible at the conference of questions would relieve their stress and therefore be received gratefully!

**UNDERSTANDING AND INTERPRETING THE NEW 'TISSUE
INTEGRITY' DRAFT WHEELCHAIR STANDARD**

Prof MW Ferguson-Pell

Centre for Disability Research and Innovation
Institute of Orthopaedics and Musculo-Skeletal Sciences
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Pressure ulcers are a major secondary medical complication experienced by many people with physical impairments. Prevention is readily achieved with the appropriate equipment and with training of the person at risk and their caregivers. In this presentation a brief historical perspective will be provided describing the development of wheelchair cushions specifically to manage tissue integrity. In recent years many new designs have evolved and reached the market. Spoilt for choice, the clinician and cushion user have few guidelines to select the wheelchair cushion characteristics most likely to meet their needs in a cost effective manner. Although manufacturers provide product information, this is subject to actual or perceived bias.

Two years ago the International Standards Organisation approved an initiative to develop standard test methods for disclosing the characteristics of wheelchair cushions in a systematic and objective fashion. The progress that has been made since then has been remarkable, resulting in the development of 11 test methods and over 20 parameters to characterise wheelchair cushions for managing tissue integrity. This work has been an international team effort involving academia and industry.

Now that we are a clear picture of the technical test methods and parameters to be used by the international community to characterise wheelchair cushions the next phase is to translate technical guidelines into information that is useful to the clinicians and user.

In this presentation we will interpret a selected group of parameters included in the standard so that they can be use effectively in clinical practice and for product comparisons.

RISK ASSESSMENT – PUTTING THEORY INTO PRACTICE

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The management of risk has become one of the central tenets of Clinical Governance and yet many practitioners remain concerned as to how best to implement the risk management doctrine. The theory of risk assessment is straightforward, namely, to identify hazards, quantify risks and to act in order to reduce risks where necessary and various standards and methodologies exist to assist the practitioner in this process. However, the experience of many practitioners is that the only effective way to learn how to undertake risk assessment is by doing it.

This presentation briefly describes a case study of the application of risk assessment to the development and provision of a wheeled mobility device modified to carry life support equipment. As an example of putting theory into practice, the presentation concentrates on one aspect of the equipment exploring the process of identification of hazards and quantification of risk.

THE SAFETY OF ADULT WHEELCHAIR USERS IN PASSENGER VEHICLES

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The safety of passengers in wheelchairs in vehicles is largely unregulated at this time. In Great Britain until very recently we have relied on a Code of Practice and Agreed Requirements with vehicle manufacturing and operating industry to set standards for the safety of wheelchair users in M2 and M3 vehicles (minibuses, buses and coaches). In the case of M1 category vehicles (cars including taxis), there are no standards in vehicle construction and use regulations.

In July 2000 the Department for Transport, Local Government and the Regions (DTLR) commissioned an extensive programme of research with the Transport Research Laboratory (TRL), to review the safety of adult wheelchair users in vehicles, to inform policy decisions on this subject. The research considers passenger road vehicles, uses instrumented dummies to establish injury levels, covers both forward and rearward facing as well as restrained and unrestrained occupants. The objective of the research is to provide an equivalent level of safety for wheelchair users as for other seated passengers. The final report is due in May 2002.

This presentation gives an insight to the current national and international vehicle legislation, and the key findings of the TRL project available at this time. The work of ISO on wheelchair tie-downs and occupant restraint systems is considered, as is the introduction of standards in the forthcoming bus construction directive. The Regulations for public transport made under the UK Disability Discrimination Act 1995 will also be covered.

All of the above will be set in the policy context of improving the safety of transport for wheelchair users, and a discussion of the issues that need to be addressed to ensure this happens.

FUNDING & WORKFORCE:
COMPROMISE BETWEEN BUDGET & PRESCRIPTION

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This paper is presented within the Risk section of the conference and the author asks the question;
Why should we compromise ?

Three main pressures to compromise are identified as:

1. Not enough staff.
2. Not enough resource – funds or facilities.
3. Exclusive eligibility criteria.

Each of these three factors introduces the element of risk to the service and possibly to clients. The extent of the risk is explored and opportunities for reducing the risk are discussed:

1. Identifying the correct staff establishment.
2. Empowerment of support staff .
3. Investment in CPD to promote competence, excellence and retention.
4. Clinical effectiveness within clinical governance.
5. Equity in criteria – levelling the postcode lottery.-Another call for National Minimum Stds.
6. Better commissioning, Service Level Agreements (SLAs) and User involvement.

The author is of the opinion that the strategy should be robust and agreed between purchasers and providers. Tactical decisions can be taken through active management within the strategy, to provide the service that is the best fit to match the demands of service users, and other pressures, as they occur throughout the contract period.

The three Wheelchair Services in North Essex group contract with 8 Primary care trusts to provide wheelchair services. The components of the SLA that forms the basis of this provision are briefly discussed, including the arrangement to take the responsibility for risk through funding deficits, away from the wheelchair service to the Chief Executives door.

The conclusion is drawn that no support can be given for compromise on prescription. It is beyond our professional code of ethics, seriously accepts an element of risk and will never satisfy client's needs.

Compromise – Never
Prioritise – Ever

**THE ACTIVITIES OF THE SCOTTISH SEATING AND WHEELCHAIR
GROUP**

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The Scottish Seating & Wheelchair Group (SSWG) has been evolving over the past 12 years to promote education and communication across the community in Scotland involved in the field of wheelchairs and seating. It has attempted to embrace all people within this community including, users, providers, commissioners, commercial sector and all other associated professional staff.

SSWG has also played a role in stimulating similar developments in the more general field of rehabilitation Technology. This presentation will give an overview of these activities of SSWG and the organisational structures involved.

OUTCOME MEASUREMENT - THE CHALLENGES AND OPPORTUNITIES

Marie Kelly

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This presentation explores the challenges and opportunities in outcome measurement that face professionals working in the field of posture and mobility.

In today's healthcare climate of clinical governance and evidence based practice there is a greater need for professional accountability and involvement of the client in the evaluation and monitoring of services. It is essential that practitioners demonstrate that assistive technology (AT) equipment such as posture and mobility aids, and their associated services, are effective and essential. AT equipment can be expensive to produce, supply and maintain and in a financially constrained NHS the need for evidence of its effectiveness is essential. Demonstration of AT effectiveness is required particularly in the light of evidence which suggests that the prevalence of AT disuse is between 30% and 50% (Scherer, 1998).

In the light of this healthcare climate outcome measurement tools are required that will evaluate the impact of assistive technology on clients daily lives. At present it is acknowledged within the AT community that there are no standard or uniform measures used to assess AT outcomes (DeRuyter, 1995 & Scherer, 1996). While there are models for measuring functional and 'quality of life' outcomes in rehabilitation such as the Functional Independence Measure (FIM) or the SF36, DeRuyter (1995) highlights that there is little knowledge about the suitability of such measures for consumers of assistive technology services. Researching and developing outcome tools that are appropriate and applicable in AT has become essential.

DeRuyter, F. (1995). Evaluating outcomes in assistive technology: do we understand the commitment? *Assistive Technology*, 7, 3-16.

Scherer, M.J. (1996). Outcomes of assistive technology use on quality of life. *Disability Rehabilitation*, 18 (9), 439-448.

Scherer, M.J. (1998). Characteristics of a meaningful outcome assessment. In *RESNA Resource Guide for Assistive technology Outcomes: Measurement Tools*. Arlington, VA: RESNA. Vol 1. 50- 59.

ESTABLISHING ROBUST PHYSICAL TESTS FOR WHEELCHAIR CUSHION
ASSESSMENT

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Pressure ulcers are a major secondary medical complication experienced by many people with physical impairments. Prevention is readily achieved with the appropriate equipment and with training of the person at risk and their caregivers. In recent years, many new cushion designs for prevention of ulcers have evolved and reached the market. There are also a plethora of methods that are used to characterise them but which yield results that are not comparable. This leaves the user/carer with few guidelines on cushion selection most likely to meet their needs in a cost-effective manner and the manufacturers with little data upon which to compare their products and improve on them.

In the last two years the International Standards Organisation committee ISO/TC 173/SC 1/WG 11 has developed 11 standard test methods and over 20 parameters for testing and disclosing the characteristics of wheelchair cushions managing tissue integrity in a systematic and objective fashion. These have recently been published as a committee draft ISO CD 16480-2 Wheelchair Seating Part 2: "Test methods for devices intended to manage tissue integrity" and is being reviewed by representatives of over 20 countries.

As part of this development process it is imperative that the test methods proposed can yield reproducible results when repeatedly performed by the same operator, and different operators, equipment and test centres. This paper reports on the experiences gained in establishing comparable results using pressure mapping between University College London in the UK and University of Pittsburgh in the USA.

EVIDENCE BASED GUIDELINES

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This presentation will describe the process of developing Clinical Guidelines for Specialised Seating/Wheelchairs.

- The request for the guidelines has originated from the BSRM (British Society of Rehabilitation Medicine) on behalf of the RCP (Royal College of Physicians).
- The requirement is for a set of brief clinical guidelines, based on research evidence where available, and supported by expert opinion and consensus views from consumers and providers.
- The process of developing the guidelines, has to follow the AGREE appraisal system in order to be clear, repeatable, and capable of being updated as necessary.
- The assistance of the PMG membership will be sought (see leaflet enclosed in conference wallet) and explained.