

# NHS WHEELCHAIR and SEATING SERVICES MAPPING PR&JECT

Final Report January 2004

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# **Foreword**

This Project Report will succeed to the extent that it enables all concerned to appreciate fully the outreach and scope of the NHS Wheelchair and Seating Services that we are presenting. Expressions such as "Fully Equipped" or "Equipment Services" have their place. But we are presenting wide-ranging Services for People of all ages, with nil, severely limited, or some loss of, independent mobility. The equipment in which they may be placed, or lie, or be seated, or seat themselves, to maximize their mobility with stability, often with the support of carers whose needs must equally be considered, is an important part, but far from the whole of the "map" we offer.

We welcome this opportunity to praise the work of all the many accomplished and compassionate individuals who provide these Services, and who, with Users, have shared with us so openly and creatively their achievements, ambitions and frustrations.

I express my warm thanks to all the members of the Project's Steering Group for their indefatigable support and wise guidance.

Sam Gallop CBE

Sam Gulif

Chair of Steering Group

#### OVERVIEW AND RECOMMENDATIONS

"To build an improved NHS requires significant investment to increase capacity."

This Report is addressed primarily to the major stakeholders involved in the direct provision and receipt of NHS Wheelchair Services\*.

It presents a number of maps of NHS Wheelchair Services as seen from the vantage points of performance, staffing and resources. The general view (historically and currently) is of Services that have never been adequately resourced to meet increasing demands and needs. Welcome new Government investments in the NHS have not so far reached these Services. There (have always been and still) are inequitable variations in provision, extensive unmet needs, and in consequence additional costs imposed elsewhere in the NHS.

The "snapshots" of excellence in this Report, demonstrate how staff, despite changing organisational environments outside their influence, remain determined to "go the extra mile" in a common endeavour "to provide services which feel personal within a framework of equity and good use of public money."

The excellent improvements generated by and with the Collaborative need to be sustained and to be extended.

Without increased equipment capacity, improvements in processes may not reduce waiting times, post-code prescribing and unmet needs.

No-one working in, or involved with, the modern NHS expects extra resources to be gifted to them. The profile of NHS Wheelchair Services must therefore be raised with Authorities and Trusts, so that the extra capacity needed will be channelled cost-effectively from Commissioners. Service Centre staff, apart from not having the quality time, cannot do this alone. They will need to collaborate with the Department, other NHS services, Suppliers, Community Equipment Services, voluntary organisations, and last but not least Users.

Within national Guidelines from the Department that foster local leadership, a mechanism involving all the major stakeholders should be created, that will raise the <a href="NHS Wheelchair Services profile cost-effectively">NHS Wheelchair Services profile cost-effectively</a> by securing and sustaining:

- Clinical Governance implemented through comprehensive National Standards continually updated to meet changing organisational and user needs
- Close inter-service collaboration supported by the establishment of a National Clinical Database
- National Marketing of the benefits of the Service
- Innovation and Research And Development
- Sensitivity to equity issues.

<sup>\*</sup> including Department of Health, Wheelchair Service Managers, Purchasing and Supplies Agency, Medicines and Health products Regulatory Agency, British Society of Rehabilitation Medicine, Centre of Rehabilitation Engineering, British Healthcare Trades Association, Chartered Society of Physiotherapy, College of Occupational Therapy, Forum of Mobility Centres, Joint Committee on Mobility for the Disabled, National Forum of Wheelchair User Groups, relevant Voluntary Organisations.

# **BACKGROUND AND FOREGROUND**

#### 1. Project Aims and Objectives

Our Wheelchair Service Mapping Project was funded by a generous and concerned Section 64 Grant from the Department of Health and was managed by *em*POWER with the Limbless Association. *em*POWER is the charities consortium, of Users of Prosthetics, Orthotics, Wheelchairs and Electronic Assistive Technology, campaigning for a "national look" based on individual needs.

Membership of the Steering Group for the Project is set out in **Appendix 1**.

The Aims of the Project were to:

- 1. Map NHS Wheelchair and Seating Services
- 2. Illuminate Best Practices
- 3. Help spread Best Practices

The project gave healthcare staff the opportunity to describe the perceived:

- · best practices of which they are justifiably proud;
- changes they would like to see introduced; and
- barriers to the introduction of those changes.

We worked alongside and in healthy communication with other ongoing welcome Government initiatives, including:

- Whizz-Kidz, in partnership with Disability North, and funded by the Department of Health, opened the first-ever children's mobility centre in Newcastle in December 2003. This Centre enables young disabled people and their families to trial equipment and seek impartial information. Similar centres will be opened jointly with Derby Mobility Centre, Bristol Disabled Living Centre, and Buckinghamshire Disability Services in Aylesbury.
- The Wheelchair Services Collaborative was launched with 45 wheelchair services teams in November 2002 to help bring about significant improvements in services. Developed in partnership with the NHS Modernisation Agency, the Department of Health and the Audit Commission, it will run until May 2004. Each team is committed to introducing sustainable improvements which will ensure that every user gets the right service at the right time.
- The National Service Framework for Older People and the emerging National Service Frameworks for Children and for Long Term Conditions, detail the Government's expectations of the services that should be available, set national standards and identify key interventions, all to raise quality and decrease variations in service.
- ICES (Integrating Community Equipment Services); a Department of Health funded initiative across health and social care to enhance community equipment services in England.

We thank all those organisations which have contributed to the successful completion of our Project, including:

- Officers at the Department of Health who have prudently yet cordially afforded us their wise guidance
- The National Wheelchair Managers Forum, together with all the staff at the Wheelchair Service and Seating Centres, and the Charities who willingly and unselfishly collaborate with them
- The British Healthcare Trades Association.
- Chartered Society of Physiotherapy
- College of Occupational Therapists
- Centre of Rehabilitation Engineering
- Medical and Healthcare Products Regulatory Agency
- Purchasing and Supplies Agency
- Audit Commission

### 2. Recent History of Wheelchair and Seating Services

The Disablement Services Authority (DSA) was established in 1987, with responsibilities which included the national management of the 23 Centres then supplying wheelchairs, and their transfer to fourteen Regional Health Authorities in April 1991 when the DSA was disbanded. The pattern of provision then became increasingly varied, the majority of services being devolved to District Health Authorities, coincidental with the introduction of the purchaser/provider split. With devolvement to Districts, the level of provision varied nationally as each District found ways of managing within limited resources. In the ensuing years, Services have been caught up in the ongoing and accelerating pace of organisational change in the NHS.

The National Prosthetic and Wheelchair Services Report 1993 – 1996<sup>1</sup>, funded by the Department of Health, advised that many of the difficulties experienced by wheelchair users and providers were due to low funding levels and limited resources. An ageing population, improvements in modern technology and rising expectations, were all adding to the demands made on services, and placing pressure on those endeavouring to provide an equable service within a finite budget. Service Users expressed a number of concerns:

- Growing inequality in service provision
- Delays to delivery of non-standard wheelchairs and seating
- Long waiting time for clinic appointments
- Unacceptable waiting times for clinic appointments
- Unacceptable waiting lists for occasional users
- Difficulty in contacting staff
- Wheelchairs too heavy
- Dissatisfaction with assessment prescription.

In March 2000, the Audit Commission published *Fully Equipped*<sup>2</sup>, a report on the provision of some forms of equipment, including wheelchairs, to older or disabled people by the NHS and Social Services in England and Wales. The report concluded that such assistive technology provided the gateway to the independence, dignity and self-esteem of older or disabled people and their carers. But the services were found to be unsatisfactory because:

- There were unexplained variations in all aspects of service provision, bearing little relation to underlying levels of need
- The quality of services owed more to custom and practice rather than to a considered view of the contribution that such services could make to the overall needs of the population
- Eligibility criteria were often unclear to users, carers, voluntary organisations and staff, and they were often applied inconsistently.

In June 2002, the Audit Commission reviewed progress in a follow-up report Assisting Independence – Fully Equipped 2002. It found that while there had been significant progress in some services, progress in improving the wheelchair service had been disappointing. Equipment services were seen as locked in a self-generating vicious circle: Commissioners neglect services ® Earmarked funding diverted to other priorities ® Commissioning sustains the status quo ® Under-managed, under-resourced services delivered ® Low profit margins for the supply industry ® Little R & D, few incentives for new market entrants ® Lack of creative service delivery. The UK lacked a national focus for services designed to support independence.

<sup>&</sup>lt;sup>1</sup> Prosthetic & Wheelchair Committee (1996) National Prosthetic & Wheelchair Services Report 1993-1996. London: Department of Health and College of Occupational Therapists.

<sup>&</sup>lt;sup>2</sup> Audit Commission, (2000) Fully Equipped. The Provision of Equipment to Older or Disabled People by the NHS AND social Services in England and Wales. London: Audit Commission.

<sup>&</sup>lt;sup>3</sup> Audit Commission, (2002) Fully Equipped. Assisting Independence. London: Audit Commission.

The direction set by subsequent Government policies and initiatives, through Primary Care Trusts and Strategic Health Authorities and Local Councils, continues to place welcome emphasis on supporting independence by improving services for older or disabled individuals, and by the establishment of common criteria nationwide.

There are now 150 Wheelchair Service and Seating Centres in England in a variety of organisational locations including Primary Care Trusts, Acute Trusts, Community Trusts, Health Care Trusts, and Mental Heath Trusts. It is estimated that there are 1.2 million wheelchair users in England – just over 2% of the population. Some 825,000 are regular users of NHS wheelchair services – with still more needing to use the service for a time limited period only.

The principles of Clinical Governance include improving standards of care, reducing variation in access to services, improving clinical decision-making and promoting evidence based practice. Putting these principles fully into practice for NHS Wheelchair Services requires the creation of a **National Clinical Data Base** (see **Appendix 2**). It is recommended that, with the participation of all stakeholders concerned, the necessary resources for the provision of such a Data Base should rapidly be forthcoming.

A significant theme throughout has been the perceived barriers to equitable prescribing and to well informed commissioning resulting from the absence of effective National Standards. We welcome the collaborative progress made to date, despite limited time and other resources, by the National Wheelchair Managers Forum and other stakeholders, towards comprehensive **National Management Standards** including legal requirements for services (www.wheelchairmanagers.nhs.uk). It is recommended that the necessary additional time and other resources should be made available to ensure further development and continuing review, in response to changing needs and wider choices, of the excellent work so far undertaken.

We also commend the work of Dr Linda Marks and her colleagues in their soon to be published, **Guidelines for Special Seating**. The Guidelines will be applicable to individuals of all ages who require a wheelchair for mobility and need additional support for postural instability or musculoskeletal deformity. They will address the needs of families /carers, assessment, prescription, delivery and review of specialised wheelchair seating.

It must be kept in mind that people who need specialised seating usually also require help with posture throughout the day and night (24 hour postural management).

#### 3. The Consultation Process

A Questionnaire, relating to the year ending 31 March 2003, was designed and sent to all known NHS Wheelchair Services. The Questionnaire was supplemented by numerous individual and group enquiries and visits.

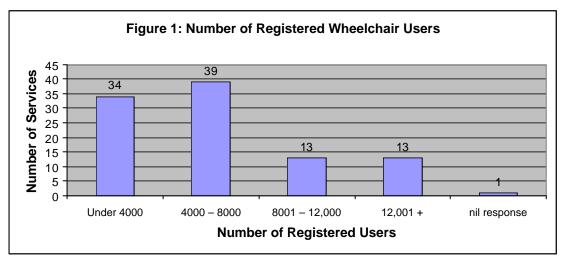
The Questionnaire covered: User characteristics; Eligibility criteria; Referral and assessment procedures; Workforce planning and practice; Environment and accommodation; Innovation and research and development; Annual budget; Commissioning; Procurement; Maintenance; Links and relationships with other services, agencies, charities, etc...; Involvement of Users; Outcomes and future planning; Waiting list numbers, times and management; Information management and communication; Clinical governance.

107 services (72%) out of the then 149 services returned completed or partially completed Questionnaires, covering 707,633 wheelchair users. Returned Questionnaires showed that five services had each merged with one other service; three of the 149 services were managed as one service; one service had three bases and operated with three different Wheelchair Maintenance Contractors. In light of this the responses are in general analysed from a base number of 100. Where  $\bf n$  is less than 100 the balance is "nil response" e.g. where  $\bf n$  is 85, nil response equals 15.

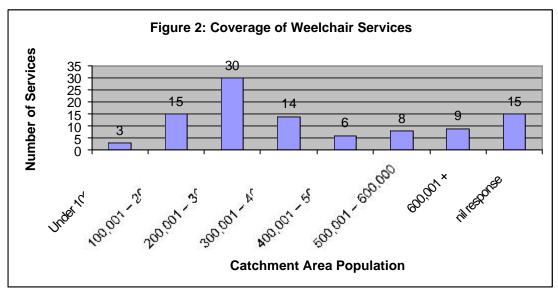
# **CENTRES**

#### 4. Centre/User Characteristics

Given the geographical variations in population densities, and the need to minimise the length of user journeys to and from Centres, the variations in numbers of registered users and populations illustrated in Figures 1 and 2 are to be expected. The majority of Wheelchair Services have between 4,000 and 8,000 registered users. The lowest number of Users recorded is 2,074. The highest number recorded is 36,011, and this particular service also has the highest number of Wheelchair Users per 1,000 of the population.

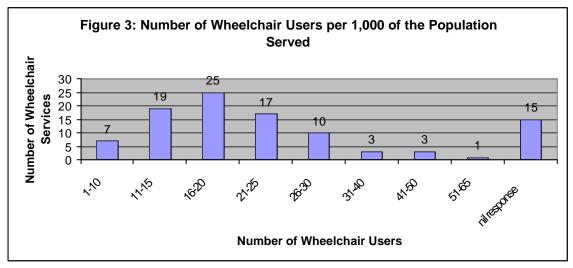


n=99



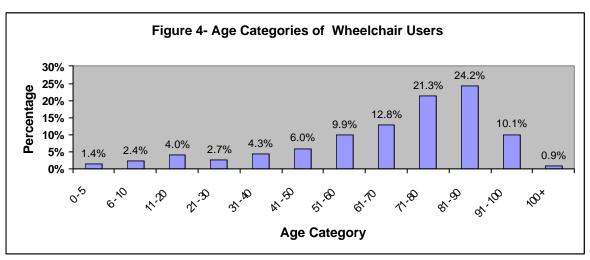
n=85

Figure 3 shows the Number of Wheelchair Users per 1,000 of the Wheelchair Service catchment Area population. The lowest number of Users recorded was seven per 1,000 of the catchment area population. The highest recorded was 65 per 1,000 of the catchment area population.



n=85

Figure 4 shows age categories of Users, confirming previous estimates that about 70% of users are over the age of 60 years. The percentages give no indication of the accompanying resources required, within or across each age group, which will depend on the client mix. One user could, and will, require at least ten times more resources than another. One will have constant needs, another varying needs. One will be a short-term another a lifetime user. The challenge to staff is to meet all these varying needs to time and equitably.



n=51

Some indication of the wide range of User needs is indicated in the following TEMPLATE of User Categories:

# 5. Staffing levels

75 services say they do not have enough staff to cope with the demands for their services, 25 feel they have enough staff. One service says: "One recommendation from "Fully Equipped" demands a "systematic re-assessment programme for all Users". This cannot take place with present staffing levels."

Work force is described in more detail in Table 1, which displays the following:

- (a) Number of staff applicable to the wheelchair service The RANGE i.e the highest value recorded to the lowest value recorded.
- (b) Number of Whole Time Equivalents (WTE) The Average.
- (c) Optimum number of staff respondents feel their wheelchair service needs The Average.

Table 1 – Workforce			
	(a) No. employed	(b) WTE	(c) Optimum Number
	RANGE	AVERAGE	AVERAGE
Manager	0 - 2	0.8	1.2
OT Senior I	0 - 4	1.2	1.7
OT Senior II	0 - 8	0.7	1
OT Basic Grade	0 - 1	0.5	1
Physiotherapist	0 - 4	0.8	0.8
Therapy Assistant	0 - 4	1	1
Technical Instructor	0 - 4	1	1.4
Clerical	0 - 15.5	3	3.1
Rehabilitation Engineer	0 - 6	1	1.5
Rehabilitation Technician	0 - 6	3	2.7
Repair and Maintenance	0 - 12	4	4.7

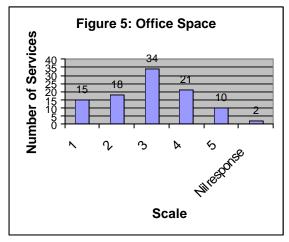
Recruitment problems are seen as no more and no less difficult in general than for any other areas of the NHS, and the Government's achievements in and programmes for remedying the shortfalls in skills and numbers in healthcare professions are recognised and appreciated. As one Minister has put it. "A lot done -- a lot to do." A perceived barrier to retaining therapy staff in wheelchair services, is restricted funding, for instance for the provision of wheeled mobility equipment and associated seating and pressure cushions. The necessity for cash-strapped services to demonstrate equitable provision to all does not align comfortably with therapists' professional desires to offer user-lead services tailored to fit desired outcomes.

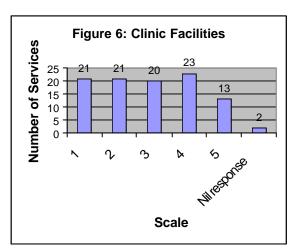
Medical input is gained in a variety of ways, including the client's General Practitioner, Rehabilitation Consultants, Orthopaedic Consultants, Neurological Consultants, and Special Seating Consultants.

#### 6. Environment/ Accommodation

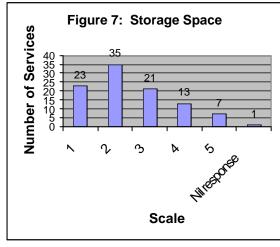
Satisfaction or Dissatisfaction with office space, clinic facilities, storage space and parking spaces is displayed in Figures 5 to 8. Satisfaction is measured on a scale of 1 to 5:

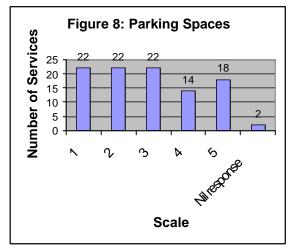
- 1 equals very dissatisfied
- 2 equals dissatisfied
- · 3 equals neither satisfied nor dissatisfied
- 4 equals satisfied
- 5 equals very satisfied.





n=98 n=98





n=99 n=98

41 of the services who responded report improvements in the accommodation/ environment of their services made during the period April 2002 to April 2003. Lack of storage space for wheelchair equipment is a common complaint. Many respondents say they have made limited improvements by reorganising space and furniture, and planning the work area to cope with demands. One service purchased a portacabin to serve as extra storage space. In others, a toy box has been placed in the clinic for children, a ramp has been fitted to the front door, and the client's toilet has been upgraded.

Improvements desired included:

- Relocation to a purpose built centre
- Proper Clinic facilities, sensitive to client privacy
- Better storage
- Air conditioning
- Ceiling track hoist
- Electric sliding doors
- Larger purpose built building
- EPIOC driving assessment centre

- Improved Warehouse Workshop facilities
- More working space for repair services
- In-house Approved Repairer
- Decontamination Area
- Improved heating and security
- Improved décor and Office Plan

# 7. Education and Training

Advances in **opportunities for education and training**, brought about through laudable initiatives from services staff who are deeply committed, include:

- Training at University of Greenwich
- Guidelines for Accredited Wheelchair Prescribers Courses
- Education and Training for Engineers
- Training for Rehabilitation Technicians
- Education, Experience and Training for Physiotherapists

(full details are available on www.kcl.ac.uk/core ).

With the support of the NHS, a range of relevant courses are open to Administrative, including IT, staff.

Table 2 shows the variety of perceived practices concerning allocation of **time for Continued Professional Development**, and indicates **the need for a national look** collaboratively by the Professional Associations concerned, and Trusts and Strategic Health Authorities.

Table 2 – Continued Professional Development Days					
	Number of CPD Days Allocated to each Profession	Nil Response (respondents who employ this profession but have not			
	RANGE	completed this section)			
Manager	1 – 24	62			
OT Senior I	0 – 40	56			
OT Senior II	2 – 30	22			
OT Basic Grade	3 – 15	6			
Physiotherapist	2 – 24	25			
Therapy Assistant	1 – 12	27			
Technical Instructor	0 – 28	30			
Clerical	0 – 24	73			
Rehabilitation Engineer	5 – 50	76			
Rehabilitation Technician	5 – 12	8			
Repair and Maintenance	4 – 5	40			

With increasing demands for services, both quantitatively and qualitatively, it would appear that there are issues concerning adequate time/opportunity for Therapist clinical review and service development. Post-graduate training opportunities are limited and many Therapists struggle to find funding or time to access the specialist experience and education necessary to acquiring comprehensive knowledge and skills in the more complex areas of wheelchair provision. These areas include awareness of lightweight and high-performance wheelchairs, powered indoor and outdoor models, special seating for postural management, and pressure-relief approaches. Knowledge of the range and application of available equipment options needs to be supported by up-to-date relevant specialist clinical information. Therapists, mindful of their professional obligation to work in areas for which they have the necessary skills and knowledge, may choose to work elsewhere or move into NHS wheelchair services management.

<sup>&</sup>quot;Awareness" (of the sensitivities of people with disability) training is ongoing, and there is healthy and spontaneous recognition that Users are partners in the service and not robot-like recipients.

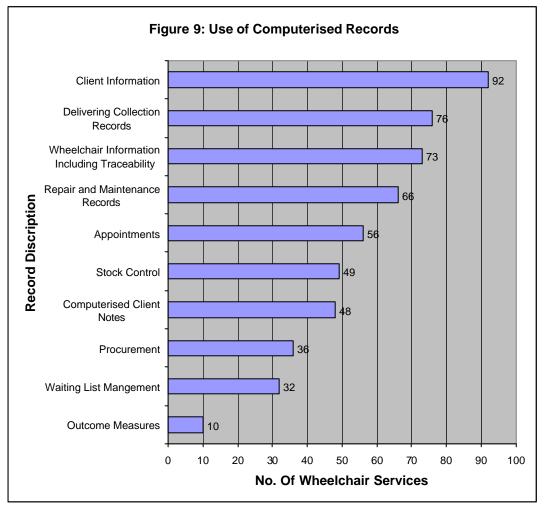
# 8. Information Technology and Communication

Table 3 shows the various computerised databases in use by Centres and the number of Users each database serves. Table 14 shows the various IT facilities available.

Table 3 – Databases used by NHS Wheelchair Services in England				
Who designed your Database?	No. of Registered Users	No. of Centres		
Sam Shaw	201,060	37		
Soft Options	99,134	17		
Unknown	86,250	10		
Rehabilitation Information Services (R.I.S)	57,356	4		
Red Wheel	46,742	6		
Medical Physics Department	36,011	1		
Designed Inhouse	26,662	1		
Ethitec	23,848	4		
Total Care	23,253	4		
Do not have access to any database	22,500	3		
Mesals	19,500	3		
Novell	13,291	1		
In Process of Getting a new IT System	13,048	2		
Limbs	12,757	2		
Mansfield House	10,000	1		
Win Help	8,000	1		
The Trusts Contracters	5,000	1		
DSC	3,221	1		
Nil response		1		
Total	707,633	100		
n=99	<del>-</del>			

Table 4- IT Facilities				
	Yes	No	Nil response	Total
Access to the Internet	81	16	3	100
Use Email	83	11	6	100
The Centre has a Website	8	81	11	100
Electronic links to repair contractor	48	48	4	100
Electronic links to procurer	10	80	10	100
Networked	71			
Stand alone	23		6	100

Figure 9 illustrates the use of computerised records.



n=93

79 respondents gave information regarding **developments they would like to see to their present IT system**, including:

- National Standard Data Set
- Quicker Updating
- Windows system
- User Categorisation
- · Links to main hospital system and Approved Repairer
- Digital camera, CD writer
- Digital image recording
- Flag system e.g. vouchers, reviews
- Better support
- Improved reports to monitor service standards
- Secure line to allow emailing of client data/ referrals
- Computer link to Regional Rehabilitation Engineering and Mobility Services (RREMS) and Approved Repairer, and supplies for Direct ordering.

The need for a reliable IT system is a recurring theme. In a follow-up interview with a Wheelchair Service Manager, the following inadequacy was highlighted

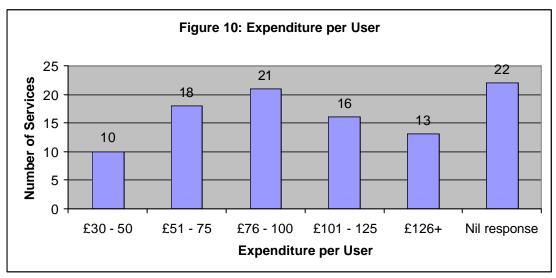
"If a Hazard Notice arrives – for example to state that a certain type of special seating is unsafe – we do not have the IT to trace which of our clients use this equipment."

# **RESOURCING**

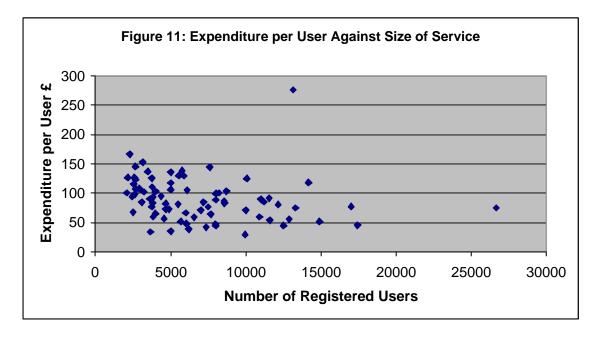
### 9. Budgets and Benchmarking

As shown in Figure 10, average expenditure per User ranged from £30 to £276 with an average of £91 per User. Figure 11 indicates variations in expenditure with size of service. Apart from their not taking into account costs incurred by the User and Carer, e.g. travel/subsistence, these figures should not be used for purposes of comparison in depth because of, for instance:

- Variations in client "mix"
- Variations in services provided e.g. a service which includes home loans will have significantly lower costs than a service which does not.



n=78



64 respondents commented on their involvement or otherwise in Budget negotiations. Some services say they are not consulted as the budget is historical or rolled over. Other responses show that consultation takes place with a variety of officers either in the Centre or the Trust.

22 Centres are not involved in any decisions regarding budget setting. Four are involved in all decisions. One Service says, "None. I have put forward a case of need, but it is not heeded".

Another Service says, "We take what we are given. Sometimes we are able to get an increase in funds for a specific need e.g. children's light weight chairs."

Those that are involved to any extent in budget setting do so by:

- Identifying pressures and priorities and agreeing baselines
- Bidding/ presenting business plans
- Meeting management accountants and setting the budget

53 services are expected to deliver annual efficiency savings, ranging from 1% to 16%, and from £5,985 - £40,000. Three services report a ceiling on individual expenditure on any one wheelchair. One service said "Maximum £1,500, but we have access to funds from a local charity for up to 12 chairs per year." Another said "We try not to go above £1,000 but have spent £3,000".

Other comments included:

- Services are generally not allowed funding for inflation or population growth or the increasing number of elderly patients
- Improvements in medical procedures and equipment result in many more complex patients, requiring lengthier assessments and costlier solutions such as "tilt in space" wheelchairs and specialised seating/cushioning
- Approximately 80% of budget is spent on equipment provision, and we have no sanction on price increases by suppliers
- We are subject to efficiency savings across the board on hospital sites, which may result in budget cuts of the order of 3% per annum year on year, resulting in cuts in equipment budgets
- Wheelchairs are mechanical devices, which means they ultimately become obsolete
  or beyond economical repair. Lack of finance to replace scrapped wheelchairs and
  invest in newer models is now evident.
- Budgetary planning never takes into account long-term needs.
- Most or all of the EPIOC budget is now spent on maintaining the existing fleet. Little finance is available to purchase new chairs.
- One can applaud the work of the Modernisation Agency and the Audit Commission, but little or no action is called for by PCT's or SHAs
- Increasing obesity bring with it increasing costs for heavy duty equipment: average cost standard wheelchair (manual) £250, heavy duty average cost £800
- Monies saved by lowest-cost competitive tendering are never re-invested into service/equipment provision.

We welcome advice that, to facilitate national bench-marking and inter-Centre comparisons, a Management Task Force is undertaking research in this area. However it is recognised that variations in client mix and geographical spread mean that bench-marking comparisons should not be pushed too far.

The following is the **not untypical view from the chairperson of a User Group**:

"Our NHS wheelchair services have been under-funded and under-resourced for many many years. Living much longer, more and more people will have mobility problems, so the demand for wheelchairs will continue to rise. Managers and staff do the best they can with limited resources. Is it now about time that the Government and Health Service Commissioners stopped treating our NHS wheelchair services like a **Cinderella Service** and looked into providing adequate resources to meet the demands of the NSF for the Elderly, thereby preventing falls, ensuring timely discharge from hospitals and assisting with the Government's aim to keep people in their own homes in the community."

# 10. Eligibility Criteria and Unmet Needs

Because of varying and significant budgetary constraints, eligibility criteria remain local, and it appears likely that they may remain so during the coming year. They are seen by the Audit Commission as a mechanism "to contain demand within available budgets". For instance, although a budget may have been fully expended well before the end of the financial year,

staff may be required to continue with assessments as if the wheelchair being prescribed was financially available, thereby increasing User disillusionment and waiting times.

Budgetary barriers to national Eligibility Criteria are indicated by the following listing of some equipment needs unmet because of lack of funding with post-code prescribing:

- Wheelchairs with alternative powered handrims
- Interfaces to environmental controls
- Ripple cushions
- Lightweight (to lift) transit wheelchairs
- Attendant controls
- · Wheelchairs which rise and descend
- EPIOCs
- EPICs
- EPOCs
- The "whole" package lights, carrier bags, rain covers, headrests for transportation, etc.
- Special buggies for children with very severe disabilities who need special seating
- Double Buggies
- Powered wheelchairs for young children
- Second Wheelchairs i.e. for clients who use a manual wheelchair for short distances or around school but need an electric wheelchair for going out. There are similar issues with regard to the provision of Trikes and wheelchair.

Prevailing inequities are illustrated in the following comment from the North London Branch of the British Polio Fellowship:

"The postcode lottery of wheelchair services is very much in evidence in the North London branch of the BPF – we cover five London Boroughs with some members travelling from Huntingdon where services generally seem first class. We have a member from Watford who has been issued with a free titanium wheelchair and another from Stevenage who could only get the same model with the voucher scheme and a lot of his own cash. Both members are in similar financial circumstances. It also appears that services available in one Borough are not available in another although we are all within the same NHS Trust."

93 services reach out and issue wheelchairs/equipment to Users in other organisations e.g. Hospitals, Nursing Homes, Residential Care, Special Schools, etc.

# 11. Commissioning

Table 5 displays the organisational location of NHS Wheelchair Services.

Table 5: Organisational Location of Wheelchair Services			
Location	No. of Services		
Primary Care Trust	61		
Acute Trust	34		
Community Trust	2		
Health Care Trust	1		
Mental Health Trust	1		
Nil response	1		
TOTAL	100		

23 Centres feel they have a significant influence on Commissioning decisions; 67 feel they do not have a significant influence and nine did not comment.

Changes that respondents would like to see in Commissioning are summarised as follows:

- More influence with Commissioners
- All PCT's to contribute financially in relation to their weighted populations
- To be able to bid successfully to fund increased Approved Repairer costs and to fund service developments e.g. equipment traceability
- Discussions regarding additional funding held at a higher strategic level; service has to compete against funding for cancer, MRI scanners etc.
- More money to meet increasing demand and for service developments
- Ring fencing
- More regular meetings and communication with one named person who has overall responsibility, plus a greater understanding of service demands
- Formal service specifications and standards
- A higher profile for wheelchair services; acknowledgement that a service can save the health system money for care
- Client led rather than budget led

Without increases in equipment budgets, welcome reductions in waiting times for assessment and prescription, will be matched by increased waiting times for delivery.

All services are required to operate a Voucher Scheme, enabling the User to contribute towards the cost of his/her wheelchair, which would otherwise be outside the scope of the NHS. Four services had at one point stopped operating the Voucher scheme for financial reasons and then re-introduced it. One service had previously stopped the Voucher scheme for 6 months to make financial savings to contribute to their PCT's financial recovery plan. In other cases the money simply ran out.

#### 12. Procurement

Table 6- Wheelchair Models Purchased					
Model		Is this N	Model Purchased?		
		Yes	No response	Total	
	User Propelled	96	4	100	
Manual Models	Attendant Push	96	4	100	
	Modular	76	24	100	
	User Propelled	79	21	100	
Basic	Attendant Push	77	23	100	
	Modular	39	61	100	
	User Propelled	97	3	100	
Lightweight	Attendant Push	65	35	100	
	Modular	44	56	100	

Table 6 shows the wide range of wheelchairs purchased.

92 out of 100 respondents feel they are **significantly involved in Procurement**. Examples of Good Practice include:

- Regular meetings held with suppliers to control quality
- OT is on trading service advisory board
- Staff attend Stoneleigh Exhibition annually for wheelchairs/ cushions/ special seating on contract and occasionally attend Naidex exhibition for options to consider.

The range of equipment to be purchased is largely a team decision of Managers, Therapists and Rehabilitation Engineers, occasionally in discussion with Suppliers, and less occasionally with Users. In other cases individuals such as the Wheelchair Service Manager/ Co-ordinator/ DSC Manager have the final decision. In one service the Commissioner is involved. In one Region, covering seven services, the range of wheelchairs purchased is decided at Regional meetings.

Practice concerning **final decisions about the wheelchair to be purchased for the individual** user varies. In the majority of services it is either a team decision (manager, therapist, rehab engineer) or a joint decision between manager and therapist. In some cases one individual has the final decision i.e. the manager, Head OT or therapist. 11 respondents stated that the Service User is involved in this decision.

82 services state that they are aware of the **PASA Purchasing Wheelchairs Best Practice Guide** (http://www.pasa.doh.gov.uk/rehabilitation/wheelchairs/).

80 services place orders directly with Manufacturers; for example:

- If the order is not available from trading service
- Call off orders
- Commitment Orders
- Three services place all orders directly with Manufacturers

Concerning **Special Seating**, seven services purchase from an NHS organisation only; 52 purchase from a Commercial Organisation only; and 39 purchase from both NHS and Commercial Organisations. 10 services manufacture in part or in full and also purchase from elsewhere.

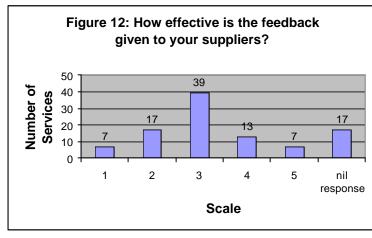


Figure 12 displays respondents' opinion on how effective is feedback given to Supplier. It is measured on the following scale:

- 1 equals very ineffective
- 2 equals ineffective
- 3 equals neither ineffective nor effective
- 4 equals effective
- 5 equals very effective

n=83

Methods of ensuring equipment is traceable include:

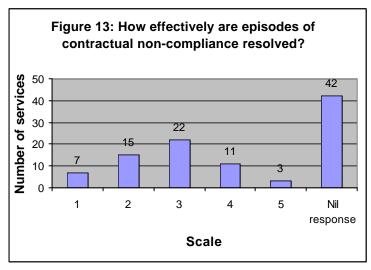
- Logging Serial Numbers/ Unique ID number, in some cases in a database, in others manual records are kept
- Tagging
- A label is attached or riveted, details inputted into computer recording repairs, reconditioning, number of issues and current status
- Electrical tagging
- Bar coding
- Manufacturer's serial number is recorded plus internal serial number and colour of equipment
- In some cases this information is kept by the Authorised Repairer
- A number of services are seeking to introduce electrical tagging.

On a follow-up enquiry one service stated that one of the main problems in **managing stock** is that Nursing Homes do not take sufficient responsibility for the wheelchairs issued to clients who live in their Nursing Homes, for instance not informing the service when a client dies so that the chair can be returned to the Wheelchair Service, and not dealing with wheelchair maintenance properly.

Concerning the **appraisal of the performance of Suppliers**, and its reporting elsewhere, the majority of respondents referred to the Purchasing and Supplies Agency (PASA) and the PASA Non-Compliance Form (http://www.pasa.doh.gov.uk/rehabilitation/wheelchairs/). Methods of appraisal include:

- Monitor Delivery notes
- Wheelchair Service Co-ordinator sends monthly outstanding reports to every Manufacturer purchased from that month.
- Regional Rehabilitation Engineering and Mobility Services (RREMS)
- Medicines and Healthcare Products Regulatory Agency (MHRA)

In House Delivery Service - weekly meetings



n=58

Figure 13 illustrates how effectively it is felt that episodes of **contractual non-compliance** are resolved on a scale of 1 to 5 where:

- 1 equals not very effectively
- 2 equals not effectively
- 3 equals neither effectively nor ineffectively
- 4 equals effectively
- 5 equals very effectively.

31 respondents provide reasons why contractual non-compliance had not been resolved effectively, summarised as follows:

- Resolution is a slow process
- · Complaints are often fobbed off
- Equipment is still arriving faulty
- It does not prevent reoccurrence
- The Contractors have had issues i.e. problems with their external Suppliers, natural disaster, staff shortages
- Contractual Non-Compliance forms take a long time to be acted on
- As yet there is no effective tool to ensure Compliance

58 respondents had episodes in the past year where outside contractors had not complied with the terms of their contract. In follow-up interviews, the following comments about **poor customer service** were received:

"There are a lot of problems with the Repair and Maintenance Contractors, who are also experiencing staff shortages. They don't recondition the number of chairs they say they will, and we had to purchase more chairs as a result. They have also not supplied information on stock levels."

"There is little or no dialogue with Centres about the non-compliance problems they are having with Manufacturers. Customer attitude leaves much to be desired, equipment is often delivered in an unsatisfactory state, and promised delivery dates are not kept."

"Although it is imperative that value for money is obtained, I suspect that constantly driving a very hard bargain with suppliers is not helpful in the longer term"

The following comments from a User about **Qualities of Service** would appear to be apposite:

"I think it is important we have wheelchair standards which cover not only the service aspects run by PCT's but also for those who retail chairs whether through the voucher scheme or not.

We should also be working closer with manufacturers to help set and achieve reasonable standards. Some of the issues that arise at the moment are because spare parts are not available. Ordering procedures are lengthy, part numbers have been changed. Whether it is PCT or private sale we are all "customers" requiring goods with a reliable and efficient after sales service.

Wheelchairs, scooters, power chairs are big business. Safety is an issue which needs to be sufficiently covered to protect those new to chair usage (carers and users). I feel that with the proper guidelines in place combined with suggested training levels some injuries from lifting chairs and usage may be alleviated. It is important within the standards and service that those who are issuing/selling the chairs are aware of the transportation adaptations available. The safety of the individual using the chair recommended should be considered both for private transport as well as on public transport, which is now more widely available. I know in principle they already are supposed to do this but do they explain about how wear and tear can affect the performance of such things as brakes? How specific do we need the standards to be for those who are receiving them to understand the issues and how important they are to wheelchair users and their carers?"

#### Another User commented:

"Notwithstanding financial constraints because of the devolvement of NHS wheelchair services, we have received excellent support, advice and provision from the Rehabilitation Engineers who are dedicated to their work, striving to maintain services despite unhelpful local criteria. One realises that financial constraints cause problems, but it would be good if chairs could be loaned to clients here while their chair is being repaired and returned."

Research most helpfully commissioned by PASA indicates that **awarding contracts by seeking the lowest competitive tender** may well in the long run be inimical to quality of service. Given the organisational turnover of staff responsible for finance and commissioning, this is an area worthy of further consideration by Managers and Commissioners in collaboration with PASA, to ensure that the long-term is taken into consideration.

The British Health Care Trades Association's view of the market for the manufacture and distribution of wheelchairs is in summary that:

- Overseas imports from the Far East, Eastern Europe and the United States have begun to dominate the market
- There has been a considerable reduction in the UK manufacturing base over the past ten years from 20 companies to six mainstream organisations, with much of the manufacturing sector also dependent on distributorships
- R&D and Innovation are being considerably jeopardised
- The NHS Model of Procurement has led to investment blight; it is price driven and based on commoditisation and rationalisation of the supply chain, with increasing difficulty for new entrants and innovation
- Framework Agreements are not seen as the optimum way forward, particularly for special seating
- A Model is needed which accommodates choice for Users and allows Prescribers reasonable freedom
- More resources are needed for education and training.

### 13. Medicines and Healthcare products Regulatory Agency

The Medicines and Healthcare products Regulatory Agency (MHRA) is the Executive Agency of the Department of Health protecting and promoting public health and patient safety by ensuring that medicines, healthcare products and medical equipment meet appropriate standards of safety, quality, performance and effectiveness, and are used safely. (www.mhra.gov.uk)

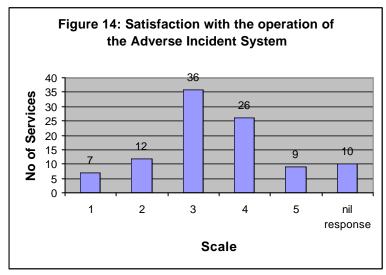


Figure 14 illustrates satisfaction or dissatisfaction with the **Adverse Incident System** measured on the following scale:

- 1 equals very dissatisfied
- 2 equals dissatisfied
- 3 equals neither satisfied nor dissatisfied
- 4 equals satisfied
- 5 equals very satisfied

n=90

28 services would appreciate, and work is in hand to secure, **further improvements in the Adverse Incident System**, including:

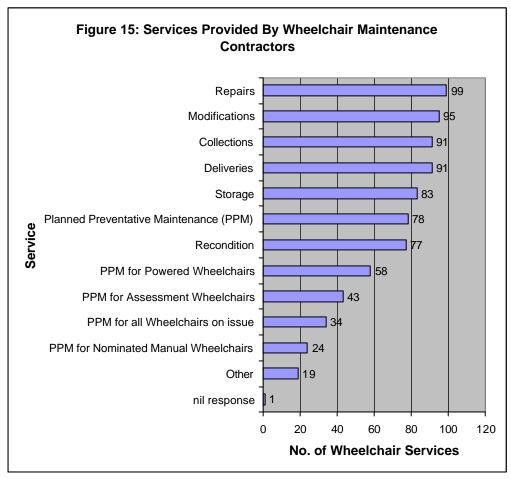
- Quicker response, clearer outcomes, demonstrable closing actions.
- Speedier investigation and response.
- Email responses for online reports.
- A quick decision to take items out of Quarantine.
- MHRA to negotiate recompense for any rectification work.
- Feedback regarding the incident, (is it recurring or one off?)

Adverse Incidents concerning Wheeled Mobility and Associated Equipment are among those reported to the Agency. As anyone who has tipped over backwards in a wheelchair and struck the back of their head will readily appreciate, there is always a balance to be achieved between mobility and stability; to avoid such incidents, effective operation of the national guidance from the MHRA is essential (see Appendix 3).

#### 14. Maintenance

Wheelchair Maintenance Contractors (WMC), the number of Wheelchair Centres each provides services to, and services provided are as follows in Table 7 and Figure 15:

Table 7: Wheelchair Maintenance Contractors (WMC) Plus number of Wheelchair Centres Each Provides Services To					
WMC	No.	WMC	No.		
A J Engineering	2	JF Alders Engineering Ltd	1		
A J Mobility	7	JR Wooddisse	4		
C F Hewardine	4	Lakesway	1		
Clark & Partners	5	Millbrook Healthcare	4		
Cleavers Mobility	4	Mobility Aids Centre	3		
DGT Services	5	Mobility Health Care	2		
East Anglican Motor plus a Sheet Metal	1	M Irving	1		
Company		_			
Elmsleigh Engineering	2	Neves Mobility	3		
Exeter Industrial Services	1	North Manchester Engineering	1		
F Millers	1	Orchard Wheelchairs Ltd	1		
Fleins Medicare	1	Rehabilitation Services Ltd	1		
		Steeper			
G Keep Ltd	1	Ross Care	3		
Gloucestershire Wheelchair Repair	1	Serco	6		
Service					
Hankins Garages	4	Tann Autos	1		
ICR Mobility	9	Trust or Hospital Estates	8		
		Department			
In House Service	9	Torbay Industrial Services	1		
Island Mobility	1	Nil response	6		



19 services report other services provided by their WMC. These include:

- 4 services state that their WMC supply accessories, such as lap straps, harnesses
- Maintenance of Red Cross Wheelchairs for short term loan
- · Maintenance clinics at schools and residential homes
- Valet Chairs for Issue
- Cushion Cleaning
- · Decontamination of returned equipment
- Client survey on performance.
- Chair reconfiguration and stock transfer
- Control boxes/ chargers/ batteries

#### 51 respondents obtain **services from sources additional to their WMC**. For example:

- Delivery and collection carried out by a separate contractor
- Reconditioning carried out by a separate contractor
- Local wheelchair dealers for voucher scheme
- Special Seating Contractors
- Approved Repairer outside the Catchment Area is used if the client is at School/ College outside the Catchment Area
- Local upholsterer for "one off adaptations"

**Monitoring of WMC's performance** is in some cases by the Regional Rehabilitation Engineering and Mobility Services (RREMS). Monitoring methods include:

- Monthly Performance Reports
- Meetings varying from weekly to quarterly
- Client satisfaction/ monitoring complaints
- Spot checks
- Audit
- Checking invoices for cost of accessories
- Incident reporting system backed up by regular review meetings in collaboration with other Wheelchair Services
- Weekly inspection of equipment and spot checks.

10 services state that **Satisfaction Questionnaires** are sent to Users to monitor performance. Some Questionnaires are sent by the Wheelchair Service (in one instance in collaboration with the User Group), while others are sent directly by the WMC. The Satisfaction Questionnaires cover areas such as courtesy and punctuality of Contractor's staff, satisfaction with quality of work, information/demonstration of equipment, and waiting times for repair visits/ collections.

32 respondents say they wish to make **changes when the WMC contract is re-tendered**; 47 do not wish to make changes and 21 did not comment. Changes desired include:

- Planned Preventative Maintenance if not already provided, or PPM to cover a wider selection of wheelchairs
- Specification for refurbishing equipment and standards for cleaning equipment
- Regular reporting system
- Management of disposal of batteries and electrical equipment
- More accountability and clear penalties for non performance
- Reinforce areas around traceability
- Quality assurance system
- Minor tweaking based on PASA Repair Contract Template.

# 15. Links and relationships

57 services reported that they **joint fund wheelchairs with other organisations**, 35 do not and 8 services did not respond. Joint funding is sensibly carried out with the following charities: Whizz-Kidz, Mobility Trust, FAFA, Multiple Sclerosis Society, Muscular Dystrophy Campaign, Motor Neurone Disease Association, Barnwood House Trust, Meningitis

Association, Peter Allis Golf Charity, Power Please, Continuing Care, Spinal Injuries Association.

In one Wheelchair Service, joint funding was with a local Comprehensive School, which needed lightweight active user chairs for two children to use in school, who would not strictly have met NHS criteria. The Wheelchair Service maintains the chairs.

56 Services carry out joint work with other organisations, 30 do not, and 14 did not respond.

Examples of **what services feel is Good Practice** when collaborating with other services, agencies, charities, are:

- Clear policy & procedures on responsibility
- Clear criteria/ guidelines
- Financial and ownership agreement
- · Information sharing, joint assessment, case conferences
- Agree ongoing maintenance
- Good communication
- User / carer Involvement
- · Common understanding of the objective
- Insurance cover
- Good Documentation
- Prompt Quotations
- Good working relationships

30 respondents give examples of issues **Obstructing Best Practice** when collaborating with other services, agencies, charities, including:

- V.A.T on health purchases
- No formal arrangements devised
- Ownership/Maintenance
- Accepting joint liability
- Other services do not want to participate
- Agreeing client's clinical need
- Expectations can be unrealistic
- Further requirements changing conditions
- Ongoing review
- Differing criteria
- Time and paperwork required to assess and agree funding

46 services have arrangements for **short-term loan of wheelchairs**, 52 services do not and two services did not answer this question. Short-term loan arrangements include:

- Red Cross
- Equipment Loan Services
- Medical Loans Department
- Community Equipment Service
- Shopmobility
- Support Services Contractor to the PCT
- Macmillan Chairs
- Dedicated technician and dedicated stock of chairs.
- Fleet of chairs and accessories available on self-referral.
- Financial support to the Red Cross.

One service has a dedicated stock of 70 chairs available for very short-term medical/ social use – up to eight wks per year loan. Issues are on a first-come, first-served basis – with minimum assessment (medical condition, height and weight) but with full handover regarding use etc. There is a full service/ maintenance/ refurbishment process. Funds were forthcoming after bidding to receptive Commissioners.

# THE RIGHT SERVICE AT THE RIGHT TIME

# 16. Waiting Times

Tables 8,9,10 and 11 show **Waiting Times, and their variations**, rightly seen as important by both staff and Users and Suppliers. Despite the variations, there is no doubt of the endeavours of Centres to ensure that the specific waiting time for each individual user is no more than that necessary for needs to be met. Complex modifications will require more than the average waiting time.

Table 8- Waiting Times (in working days) between URGENT referral and assessment					
	AVE.	HIGHEST	LOWEST		
MANUAL	7	69	1		
SELF PROPELLING 7 69 1					
POWERED	15	69	1		
EPIOC	29	365	2		

Table 9- Waiting Times (in working days) between ROUTINE referral and assessment					
	AVE.	HIGHEST	LOWEST		
MANUAL	44	280	1		
SELF PROPELLING	42	280	2		
POWERED	66	400	3		
EPIOC	131	730	5		

Table 10- Waiting Time (in working days) between URGENT assessment and delivery of wheelchair						
AVE. HIGHEST LOWEST						
MANUAL	4	43	0			
SELF PROPELLING	5	43	0			
POWERED 13 60 1						
EPIOC	23	365	1			

Table 11- Waiting Time (in working days) between ROUTINE assessment and delivery of wheelchair							
	AVE. HIGHEST LOWEST						
MANUAL	19	100	0				
SELF PROPELLING 19 90 0							
POWERED 36 200 2							
EPIOC	48	365	4				

#### Main causes of delays include:

- Manufacturer delays
- Repairer delays
- Staff sickness 1 service said the PCT would not fund a locum
- Errors with order/ lost items/ defective equipment arriving
- Items not in stock inadequate storage
- Insufficient staff levels
- No funding until next financial year
- Complex procedures for EPIOC assessments
- Equipment that requires specialised modifications or parts
- Inappropriate referrals

- Ensuring correct training is given before introducing new products into the field
- Incomplete referral forms

#### 17. Referrals & Response Times

Table 12 – Sources of Referrals				
	Number of Wheelchair Services that take referrals			
Source	from this source			
GP	96			
Occupational Therapist	93			
Consultant	90			
Physiotherapist	89			
Community Therapist	88			
District Nurse	71			
User	48			
Nursing Home	35			
Other	24			
Nil response	1			
Total	100			
n=99				

Table 12 shows the sources of referrals. "Other" includes:

- Social workers
- Carers, relatives
- Any health care professional
- Schools
- Health visitors
- Sheltered housing scheme managers
- Key workers
- Macmillan nurses, specialist nurses
- Charities e.g. Whizz-Kidz
- Occupational Therapists from elsewhere in the Trust
- Accredited Professionals
- Respiratory Nurses

On average, Wheelchair Services receive 14% of their referral forms incomplete, which consequently contributes to delays in service delivery. One Wheelchair Service reports 50% incomplete referral forms. Another Service reports 25% of referral forms incomplete (largely due to GP's and Nurses not filling in height and weight sections on the form) and is considering introducing an electronic referral system to solve this problem. Services received on average 809 re-referrals in the period April 2002 to March 2003, and an average of 1015 new referrals. The highest numbers of referrals and new referrals received by a wheelchair service were 7320 and 6056 respectively.

Despite tight budgets and increasing demands for services, Centres have praiseworthily agreed the following minimum national standards from referral through to delivery in working days (wds):

From referral to assessment From Prescription to Delivery

- 10 wds from receipt of referral17 wds for locally held stock
- 30 wds for orders from manufacturers
- 6 to 13 weeks for made to measure and special seating.

#### Main causes of delays are:

- Manufacturer lead time/poor response from manufacturers
- Incomplete referral forms
- Insufficient Staff levels
- Staff leave

- Staff sickness one PCT for instance would not fund a locum
- Errors with order/lost items/defective equipment supplied
- Items not in stock

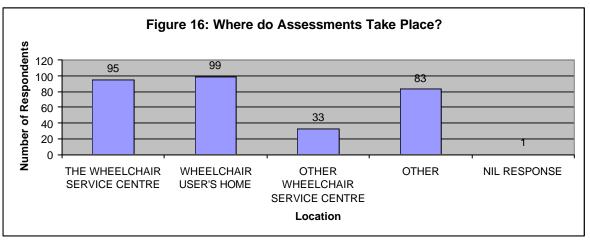
Concerning **inappropriate referrals**, 36 Services say that one definition is that the client does not meet Eligibility Criteria. Other instances whereby a referral is defined inappropriate are:

- Incomplete referral forms
- Equipment not provided e.g. electrically powered outdoor chairs, scooters, static seating
- Short term loan do not have a permanent and substantial mobility need
- If the wheelchair will be used for restraint and not mobility
- If the client is undergoing rehabilitation
- Reguests not appropriate for Medical Condition
- From a non-appraised source
- Environment is unsafe
- Poor judgement by referrer e.g. client does not want to have a wheelchair
- Equipment requested is unsafe
- There are no available carers
- Residential or Nursing homes for transit purpose
- No storage
- The referral is from a Social Worker

Methods of dealing with inappropriate referrals include:

- Clarifying with the referrer by telephone or letter, occasionally enclosing the Eligibility Criteria
- Clarifying with both referrer and client
- Advising alternatives e.g. refer to the voluntary sector or forward referral on to the correct district if it is outside the catchment area
- Return the incomplete form to the referrer for completion
- One Service said "Sometimes we offer the client an assessment so that they are able to see that a wheelchair will not be appropriate."

#### 18. Assessment



#### N=99

Because of varying client needs and environments, there can be no single optimum location for Assessments. Figure 16 indicates where assessments take place. "Other" locations include:

- Educational locations schools (special and mainstream), colleges and adult training centres
- Day centres

- Hospitals, Rehabilitation Units, Specialised Orthotic Services, Outreach Community Hospitals, District Clinics, Hospices
- Child Development Centres
- Mobility centres
- · Places of employment
- Commercial Suppliers

Many services expressed dissatisfaction with the adequacies of their assessment facilities (See Section 6).

Table 13 – Who carries out assessment after referral?				
Profession	No. of Wheelchair Services			
GP	0			
District Nurse	7			
Social Services	3			
Occupational Therapist	94			
Rehabilitation Engineer	85			
Physiotherapist	52			
Consultant	24			
Other	33			
Nil Response	1			
Total	100			
n=99				

Table 13 displays responses to the Question "Who carries out assessment after referral?" "Other" includes:

- Accredited prescribers
- Technical Instructors
- Seating Orthotist
- Clinical Scientist
- Joint assessments carried out with another professional involved e.g. Paediatric Physiotherapist

Aspects of the **User's Lifestyle**, which are of course relevant to Outcome Measures (see Section 19) taken in consideration during assessment include:

- Transport
- Environment- e.g. home and garden access, rural/urban.
- Education
- Level of Activity
- Leisure- hobbies, sport
- Employment
- Individual needs
- Social Issues- for example do they live alone?
- Preference
- Expectation
- Motivation
- · Family responsibilities- do they have children at home?
- Psychological
- Leisure and social life
- Quality of life (EPIOC)
- To enable the client to be as independent as possible
- Future aspirations

One Service says they consider "Wheelchair Aesthetics – Paint Effects" when assessing clients. Eight Services describe their wheelchair assessment for clients as "holistic". One Service says their holistic assessment is based on the "Sanderson & Reed Model of Occupational Therapy". Several say that lifestyle needs are met as much as possible within Eligibility Criteria. One respondent states "as many as we can…remembering it is our duty to provide <u>basic</u> mobility". One service states they do not provide equipment specifically for sport or work needs, whilst another states they do not provide for sport, work or education.

New regulations mean that in future trains, buses and taxis will all have to be designed so that most wheelchair users can travel in them. The British Healthcare Trades Association has produced a helpful Wheelchair User's Guide to Public Transport entitled "Get Wheelchair Wise". Other useful contacts are the Mobility & Inclusion Unit of the Department of the Environment Tel:020 7944 3277; the Community Transport Association Tel: 0161 3678780 and Tripscope Tel: 08457 585641.

All services take the **needs of the Carer** into consideration. Health and physical issues (height and weight) and the ability to manage wheelchair equipment feature most frequently. Other considerations include:

- Transfer
- Environment
- Cleaning Chair
- · Number of children living at home
- Cognition
- Priorities/ Expectations
- Age is the carer elderly and frail, or a young carer- perhaps a child?
- Is the carer family/neighbour, or professional?
- The amount of care given to the user how, when, where, what
- Training and handover of equipment
- Psvchological

Three respondents confirm that meeting the needs of the carer is dependent on funding and is considered within available resources. One service says "....as far as possible. However we do not provide equipment specifically for the carer e.g. lightweight transit chair for the carer who has difficulty lifting a chair into/out of a car boot. In cases such as these, we would normally issue a voucher."

#### 19. Users and Outcomes

The majority of Services have a **User Group**. Those that do not (there can be recruitment difficulties despite continued invitations/publicity) and those that do, **further engage Users** in their Service by various means including:

- Local general disability groups
- Client satisfaction surveys and suggestion boxes
- Product evaluation group
- A User Panel whose members read User Information and provide feedback
- Focus groups
- Publicising the complaints procedure
- Including Users in consideration of complaints
- Meetings with Commissioners
- Internet

TEMPLATE Terms of Reference for a User Group are available on www.chairpower.org.

User Involvement in specific activities is described in Table 14.

Table 14: User Involvement						
Are User Groups or Individual	Yes	No	Nil response	Total		
Users involved in?						
Budget Setting	5	76	19	100		
Commissioning	8	71	21	100		
Procurement	12	69	19	100		
Setting of Eligibility Criteria	31	48	21	100		

#### Methods of involving Carers include:

- User Group/ focus groups
- Assessment process
- Satisfaction surveys/ Comments & suggestion boxes
- Events
- One service involves Carers when the WMC contract is re-tendered

42 services report having conducted **User Satisfaction Surveys** in the past year. Other best practices include:

- Following a Survey of User Satisfaction with the Repair Service, Contractor's staff now attend Customer Service courses
- A survey is sent to every client three months after delivery. Any issues raised are dealt with. Results are analysed for any trends. Feedback is given to the WMC Manager, during contract review, or immediately if Urgent Action is required.
- A pre-paid postcard is sent to every new client to complete and return. As the
  postcard is easy for clients to fill in/return, this survey has high response rate.

#### Methods of informing Users/Carers about Repair Procedures include:

- Printed information at issue,
- Letter in event of Repairer details changing,
- Sticky label on each wheelchair with Repairer contact details,
- Card by the phone with User's registration number, repairer telephone details, etc.
- Repairer details in Annual Newsletter sent to all clients.

#### Examples of **Outcome Measurement Tools** include:

- Audit
- Risk Assessment Forms
- Satisfaction Questionnaires
- Goal Orientated Documentation
- An outcome orientated intervention form used with each client seen
- Using "before and after" photographs to assess the impact of Special Seating on Posture

#### The similarity between:

- TEMPLATE Outcome Measures and Questionnaire (Appendix 4), and
- an Outcome Measurement Tool (FEW) which is the subject of further appraisal/application by Users in collaboration with colleagues in the United States (Appendix 5)

is encouraging.

The relevance of satisfactory outcomes to the objectives of the National Service Framework for Older People is indicated in **Appendix 6**.

Unbiassed professional advice, is of course essential for actual and potential Users of wheelchairs and their Carers. Useful (and free) sources of information and advice, often with opportunities to try out, include: Department of Transport Mobility Unit (www.mobility-unit.dtiri.gsi.gov.uk); Disabled Living Centres Council (www.dlcc.org.uk); Disabled Living Foundation (www.dlf.org.uk); Motability (www.motability.co.uk); National Federation of Shopmobility (www.justmobility.co.uk/shop); Ricability (www.ricability.org.uk).

# 20. Innovation and Research and Development

52 services organise internal demonstrations of new Wheelchair Equipment for Service Users. 38 formally assess the impact of new wheelchair technology and 23 have participated in Research Projects.

One Project is being undertaken Regionally, with all Wheelchair Services in that Region sharing funding. The research is undertaken by a Rehabilitation Engineer, and includes:

- Criteria Analysis of Wheelchairs and Seating under various categories i.e. Children's Wheelchairs, comfort Chairs and EPIOCS
- Designing Assessment Equipment e.g. stability ramps
- Computer Software reduces the need of manual handling

#### Other Projects include:

- Audit into Pressure Relief Cushion Provision, which led to the introduction of a "Pressure Relief Protocol"
- Ongoing research into lifestyle outcomes for EPIOC users
- London Access Project work
- EPIOC Review by Wheelchair Therapist of posture, tissue viability etc
- Regular equipment audits
- Evaluation of equipment performance, disability and cost effectiveness; equipment that did not perform well was excluded from the stock list.

# **CLINICAL GOVERNANCE**

# 21. Department of Health Policy

The main components of Clinical Governance are:

- Clear lines of responsibility and accountability for the overall quality of care
- A comprehensive programme of quality improvement systems
- Education and Training plans
- Clear policies for managing risk
- Integrated procedures for all professional groups to identify and remedy poor performance

With these components in mind Centres were asked about aspects of **Department of Health Policy** that they felt needed clarification. Responses range far wider than Departmental Policy and give useful insights into a Wheelchair Centre's view of the map:

- Provision to Nursing Homes
- · Competencies for staff and skill mix
- Limits of funding for individuals
- MHRA instructions
- Clear lines of responsibility and accountability for Equipment provision
- Range of Equipment purchased
- Budgets per Capita
- EPIOCS issued through the Voucher Scheme
- · Training Days and Budget
- Risk Assessment
- National Standards
- Out of Area Treatment System
- Joint Funding
- Disposal of Wheelchairs

Some respondents said they had not yet seen any Policy on Wheelchair Services.

These understandable responses illustrate the core need for consideration of ways and means of further securing national strategic approaches to NHS Wheelchair Services, which would foster local responsibilities and initiatives.

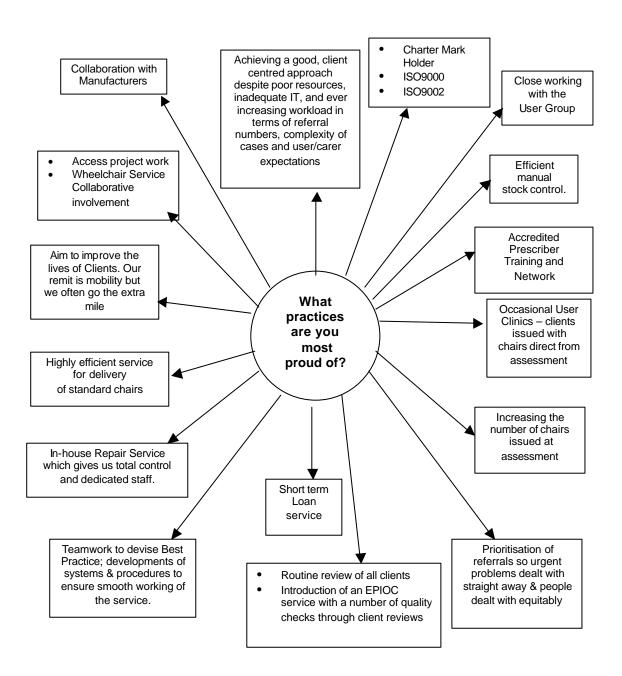
Within national Guidelines from the Department fostering local leadership, a mechanism involving all the major stakeholders should be created, which will raise the <a href="NHS Wheelchair Services profile cost-effectively">NHS Wheelchair Services profile cost-effectively</a> by securing and sustaining:

- Clinical Governance implemented through comprehensive National Standards continually updated to meet changing organisational and user needs
- Close inter-service collaboration supported by the establishment of a National Clinical Database
- National Marketing of the benefits of the Service
- Innovation and Research and Development
- Sensitivity to equity issues.

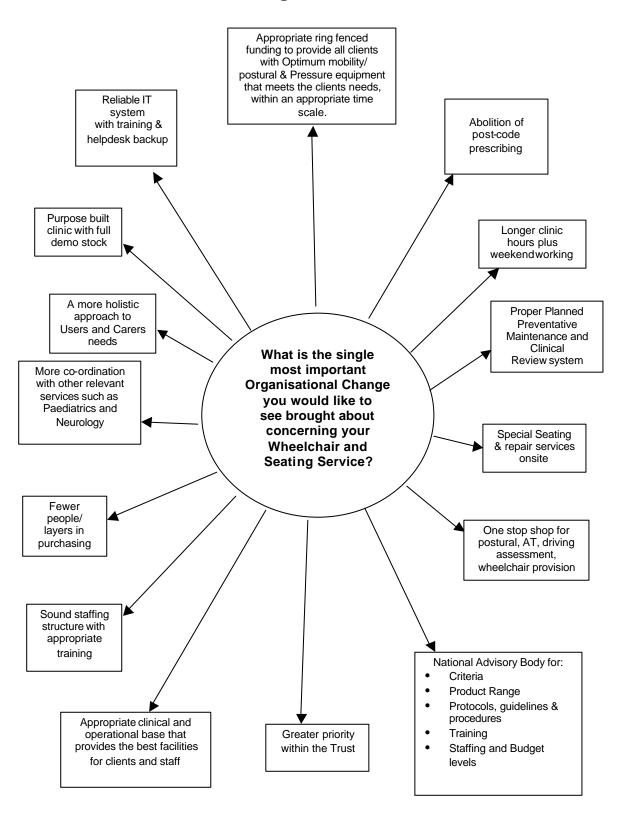
# 22. Best Practice and the Need for Change

Centres were asked to describe the **practices in which they took most pride** and the **changes needed for their introduction**. Their responses are summarised in the following Figures 17 and 18.

# Figure 17 Best Practices



# Figure 18 Changes Needed



# 24. Snapshots of Excellence

We conclude our Report with just a few characteristic Snapshots of Excellence in Wheelchair Services. We could give many, many more, typical of the skilled, compassionate and sustained services generously given, but rarely in the limelight of the media.

Good practice and collaboration typifies the "around the clock" Postural Management and Mobility Clinic operated by the London Borough of GREENWICH and the Wheelchair Service of the Greenwich Primary Trust. Entitled "Therapy in Partnership" they provide a seating and postural service for children and young adults. Helpful advice and resources are given by the Greenwich branch of Sure Start, a Government initiative committed to delivering the best start in life for every child. The overall purpose is to assess the sitting ability, transfers, and the means of getting about; to provide the appropriate seats or carriages to ensure comfort, good posture and positioning; with night support if required. The expertise and care of several disciplines is brought together, with the involvement of all relevant professionals, carers, children and seating representatives. There is a supply of assessment seats on site. Clinics are held once a month. Regular attendees include Paediatric Physiotherapists, Wheelchair Services Manager, Rehabilitation Engineers and Technicians, Social Services Occupational Therapists, Sure Start Managers.

COVENTRY Wheelchair Service is very much concerned with the lifestyle needs of its 6,100 clients, so it is not surprising that it is both policy and practice to ensure that the User Group is involved in the service. The Group includes varied users of the service, carers, representatives from Coventry PCT management, and the Therapy Team. The Group joins in Contract discussions, in organising Events, in the writing of all the literature that is produced within the Department, and has also been involved in the recruitment/interview process for Therapy staff.

ROEHAMPTON Wheelchair Service and Special Seating Rehabilitation Engineering Workshop within the South West London Community NHS Trust, provide a service for children and adults with complex postural needs, who are unable to maintain their seating position in a standard wheelchair or buggy. The highly skilled and innovative team, led by a consultant in rehabilitation, includes a physiotherapist, an occupational therapist, a rehabilitation engineer and technicians. Each client receives an assessment based on individual needs; all aspects of daily life are taken into consideration. If commercially available equipment does not meet the client's needs, the Workshop will design and manufacture a range of custom-made seating systems. All emergency repairs are within 24 hours.

SANDWELL Wheelchair Service, part of Oldbury & Smethwick Primary Care Trust, responded rapidly and effectively, when they realised during assessments that a recurring issue was the difficulties a Carer who is elderly or disabled will have in pushing a non-powered wheelchair. Following a successful evaluation by the regional rehabilitation engineering department, the TGA powerpack was introduced, to take the effort out of pushing. The detachable powerpack incorporates a wheeled motor and battery pack fitted to the rear of the wheelchair. The Carer is empowered through a control box fitted to the push handles. There are now more than 350 powerpacks on permanent issue. A satisfaction survey has confirmed the benefits to the lifestyle of both User and Carer. Mechanical inspection is carried out annually by district approved repairers. North Warwickshire and Rugby are among other services providing powerpacks against established criteria.

Liz Francis, Brenda Coe, and all the other highly valued members of the team at BARNET PCT, working in lively and two-way collaboration with User group chair Mike Nash, have maintained the considerable reduction in waiting lists achieved from earlier changes. The barrier of lack of space was imaginatively removed by innovatory drop-in clinics across the borough; so successfully that friendly Finchley Memorial Hospital now hosts their regular Saturday clinics, at each of which a dozen or more clients are assessed for same day delivery. Other developments feature consistent access criteria, publicising specialist and therapy services across London, and interdisciplinary models for specialist and therapy services for children and for older people.

Serving 19,000 clients in eight PCTs, Hazel Derbyshire and her team based in a purpose-built unit at the Royal PRESTON Hospital, are justifiably proud to have been four times Charter Mark winners, recognising many improvements in their practices, including:- a quarterly Therapists Newsletter circulated widely to 130 Therapists in the Community and mentioning in the latest issue that all areas were on target for the issue of EPICs and EPIOCs; basic, advanced and paediatric training sessions for Therapists; Open days at which Therapists and Users test-drive EPIOCs on the Centre's own "test track"; accreditation to the new ISO 9000 2000 Quality Standards with the Assessor commenting that a lot of work had been completed in a very short time; and a Wheelchair Prescriber's Handbook which has proved successful in regulating issues of specific models.

In addition to their pride in their multidisciplinary team approach with User Group participation, and training for accredited therapists, Samantha Sterling and her colleagues at Chapel Allerton Hospital in LEEDS are rightly enthused about the introduction of their Partial Booking system. To quote Samantha: "Partial Booking means we do not allocate an appointment without discussion beforehand with the Wheelchair User. When we receive a request for a general appointment, and the person needs to come into clinic, then we write to them asking them to contact our Appointments Line to agree a time and date that suits them. When they telephone we advise them which sessions are suitable for the type of appointment they need and both parties agree an appointment. This has reduced the number of people who DNA as they have hopefully chosen a time convenient to them, and avoids calling people who do not want to attend."

Linda Hearsey, Jane Sledge, Gary Williams and their colleagues in the WIRRAL have introduced two major measures to ensure that the 12,000-plus pieces of equipment issued from their two Centres are readily traceable, identifiable and maintained in accordance with the MHRA Guidelines. They were the first to fit electronic barcodes universally, and their new planned preventive maintenance programme has ensured the checking of every piece of equipment issued. The level of care given to all their service users has been further enhanced by their comprehensive User Pack, in A4 size in large print issued with every wheelchair, an integral part in the development of which was played by the User Group.

The team at the EAST BERKS Service based at St Mark's Hospital in Maidenhead, are proud of the improvements they have been able to achieve in Waiting Times for Appointments, Time Management and Speedy Delivery of Wheelchairs. They managed these improvements by:

- Identifying times of increased numbers of Referrals and using "Locums "with Wheelchair experience to reduce these "peaks" where possible and within "Budgetary Restraints".
- Strengthening the vital Admin team to free clinicians from unnecessary paperwork
- Fostering joint working whilst clearly identifying senior Management and Clinician roles
- "Bulk Purchasing" of Equipment and stock on site to enable Patients to leave with a Wheelchair immediately following assessment.

They continue to seek to reduce the level of "Inappropriate" referrals and DNAs/ Cancellations wherever possible.

The HAVERING PCT Service team are proud that they have driven down waiting times for their clients. In September 2001, Zac Arif, Director of London Primary and Community Services Access Project, took Havering Wheelchair Service on as a pilot site. Previously it took 70 days for a referral to be processed, then 192 days for a client to be seen in clinic, and then depending on stock availability anywhere between 7 & 365 days to receive equipment. Redesign enabled Havering to screen and process referrals in 2-4 days. Clients were offered an appointment and seen in clinic 16-20 days after their referral had been screened. Up until August of this year there was no waiting list for clients without an appointment. Redesign work goes on – the next aim is to deliver equipment to clients at their first appointment or in the shortest possible time thereafter. However, with increased throughput, Havering have hit financial constraints, and now can book only high risk clients. Much more involvement with Commissioners will need to take place in the future to draw up Service Level Agreements and secure increased funding.

Despite not having an in-house seating service or an 'assessment' vehicle for satellite clinics as she would wish, Susan Strong in SOUTHAMPTON is rightly proud of the personalised

service given to clients by all her committed and skilled staff, their innovative approach to problem-solving, and the close working partnership with their authorised repairer.

The EXETER Wheelchair Service - reaching out to clients throughout Devon & Somerset – has recently made many improvements, including:

- working ever more closely with their Commissioners with the added values of reducing waiting times and increasing resources
- 70% of direct issue equipment is issued within 10 working days
- Improved communication with Referrers to the Service by setting up local Forums

as a springboard to further service developments/improvements.

The Wheelchair Service based at the Queen Elizabeth Hospital in KING'S LYNN ensures that all clients are individually assessed by a Wheelchair Service Occupational Therapist. Referrals are prioritised into two simple categories of priority or non-priority users, with the resources being targeted at priority users to ensure a sustainable service throughout the year. All appointments are sent within ten working days with stock wheelchairs being delivered within ten days of the client's individual assessment. At the time of the assessment all the clients are given a booklet which incorporates the conditions of the loan, the approved repairer details and a named contact person should the need arise.

GRIMSBY'S team modestly draw attention to their computerised "open house" review system, with users and carers requesting their own reviews, and which also flags reviews for powered wheelchair users (clinical and equipment) - annually; adults with special seating – annually or six monthly; children - every term in school or at clinic. They also have developed a risk assessment tool for all standard chair users; filled in at the original assessment and based on usage level/ weight/ safety/ dependency on chair and the experienced OT's clinical judgement. They are rightly proud of how they involve carers at the point of assessment; only possible because they have a very experienced OT and RE and a workshop on site where equipment can be readily adapted. They visit an out-of-area special needs school and joint fund school equipment for children. They also hope to joint fund for a Dystrophy patient and look forward to further collaboration with the Muscular Dystrophy Association."

Manager Nila Panchal and all the other members of the dedicated team at DONCASTER Wheelchair Services, within the Doncaster and South Humberside Healthcare NHS Trust, despite accommodation difficulties, are rightly proud of their In-House Repair Service, set up when a Focus Group of Service Users identified the need for a local drop-in service. The repair/maintenance workshop and the stores are part of the Wheelchair and Special Seating Services. Users can bring their chairs in for repair when it suits them instead of having to wait all day at home. Clinicians and technicians work together so that Users receive their chairs after assessment, adjusted and adapted to meet their needs, on the same day. The service is cost effective with high quality standards. There is maximum stock utilisation, prompt response to Users' needs, and total flexibility to meet seasonal fluctuations in demand. Joint working between clinicians and technicians leads to seamless service provision. Users and Carers have an excellent rapport with staff and are happy to drop-in for the maintenance of their chairs.

Modestly attributing improvements by her team at the HILLINGDON Independent Living Centre to the opportunities afforded by the Collaborative project, Heather Russell writes: "We have changed our range of equipment, to improve the service for users - we wanted quicker delivery times and spares availability, and a lighter wheelchair and more flexible prescription to meet user needs more closely. We changed to Invacare products for the trial Zipper and Ben9 Ranges and the response from users has been good. We have fewer clients wanting to use the voucher scheme and fewer complaints about the weight of the chairs. Obviously these chairs don't suit everyone but everyone on the trial was happy to feedback and be honest about the good and not so good points. User questionnaires on the service were issued this year; so far the indications are a high satisfaction with the service overall, which is encouraging. Lots more challenges ahead!"

The caring commitment of WEST KENT NHS & Social Care Trust through Kathryn Davis, Business/Equipment Service Manager, and Jan Aluwalia, Wheelchair Service Manager, and

their team, serving nearly 10,000 clients from their two bases at the DSC Medway Maritime Hospital and the Stone House Hospital in Dartford, is evidenced by their tangible support for and participation in the Countywide Wheelchair User Group and Forum, which helps develop all six NHS Wheelchair services in Kent. Eligibility Criteria have been reviewed, and arrangements for service and repair are under review. The Service plays a key role in Clinical Governance, and early in 2004 will, in collaboration with other colleagues and users, seek to progress still further the effective use of evidence-based clinical information.

GATESHEAD Wheelchair and Loan Equipment Service is on the "fast track" using "Mesals" (Managing Equipment Stores and Loan System) software to trace the location and history of every piece of equipment issued. A dedicated landline is used to take referrals from professional staff in the field and hospitals. The referrals are input direct on to computer which places the order with Stores. All equipment is bar coded prior to issue. Reports can be run for instance on stock levels, how many items of certain equipment have been issued, collection rates, speed of delivery, etc. The system is vital to the current integration with Social Services. When equipment is issued the computer generates a delivery/collection note detailing the equipment being delivered, and the telephone numbers for repairs, loan equipment returns and enquiries. At Gateshead they are also rightly proud that delivery of equipment within three days is at 96%, return of equipment for recycling is 79%, and there is no waiting list for standard wheelchairs.

CHICESTER'S Senior Occupational Therapist Jean Curry attributes much of the team's success to their having minimal turnover of staff, and knowing their Western Sussex "territory" and the needs of their clients. When we pressed Jean further, in a letter (the office does not yet have e-mail) Jean wrote:

- We have no waiting lists for either an assessment or equipment provision
- We he been able to arrange join funding of expensive equipment such as tilt in space power chairs with the generous help of the local Multiple Sclerosis Society and Motor Neurone Disease Association
- We respond quickly to all referrals, give clients a date when they will be assessed, and assure them their problems are being attended to. We have very few complaints as a result.

Kath Griffiths and all the skilled members of the CREWE Wheelchair Assessment Centre Team, serving 5,000 Users in Mid Cheshire, have rightly earned their Charter Mark in conjunction with colleagues in Therapy Services for excellence, despite not having a purpose-built Centre incorporating an authorised repair service. A sound foundation for their achievements is their wide-ranging and constructive monthly half-day Clinical Governance sessions, and their outstanding involvement in and support of audit, all structured round both User and staff needs.

ROTHERHAM PCT wheelchair services cheerfully remind us that Rome was not built in a day, but one can see that they will have progressed many exciting developments and much good work by June 2004, when with other key partners they move into brand new, bespoke and fully accessible Community Health and Equipment Services (CHEWS) Premises. Manager Richard Nicholson is certain that the next 6-12 months will be extremely fruitful. All staff have extensive and ongoing professional development including Disability Awareness training. They intend to meet the NWMF standards in every area of the service. Enterprisingly, the PCT, and Rotherham District General Hospital Trust, have set up a Bariatric (Obesity) Care Pathway development group to meet the care needs and cost pressures of the increasing number of obese users; it is recommended to seek funding to hold a small range of Bariatric equipment in CHEWS to prevent delayed discharges and to meet Health and Safety requirements.

WEST DORSET'S wheelchair services have rightly twice been awarded the Charter Mark for Excellence in their "open-door" public services. This multi-disciplinary dedicated team, from their purpose-built Centre in Dorchester, have an active client base of 3,500, with an age range from 2 to 101 years. Many assessments are carried out in the client's home. They have excellent working relationships with their repairs service. Their operation management group has a long history of service user involvement, with clients being actively involved in decision-making and service development.

The Wheelchair and Special Seating Service at BRISTOL consolidated its wheelchair repair service in-house a number of years ago. With impetus from the User Group at the time, and support from the Health Authorities, an extended service was affordable. Underpinned by improved quality of wheelchairs and enhanced recycling, and supported by well qualified field service engineers, the team based at Bristol offer a "standard" response within two working days, "urgent" the same day, and an "emergency" service within one hour, available all day, everyday. They believe they were the first to bring the repair service in house and to offer access to repairs 24/7. They recognise the importance of the wheelchair to their service users and the fact that breakdowns, whenever they occur, may need immediate attention. In practice, due to the standard of equipment that they issue in the first place, they have very little demand for the out of hours service.

Whilst additional funding (e.g. for add-on power packs and improved IT system) would always be welcome, Margaret Smith and the press-on team at CALDERDALE Wheelchair Services based in Halifax, are especially proud that despite increasing financial and time pressures a level of service has been maintained which meets the primary needs of their 2700 wheelchair users. Users are "very happy" with the Repair Service. Waiting times for appointments and equipment have been managed to a minimum and relationships with users and carers continue to be of a high standard. The excellent short-term loan service has been further improved by close collaboration with the local Red Cross.

Like many wheelchair services, SOUTH TEES struggles within available resources to meet all client needs. The wide range provided of manual and powered wheelchairs, includes Standard, Lightweight self-propelling and transit, Heavy duty, Lightweight recliners SA8/9,Active us er, Powered with tilt-in-space, Powered recline, and Swiftstyle buggy. Rehab Engineers liaise closely to ensure an efficient and effective repair and maintenance service. Audit is an integral part of the sustained commitment to improve. The client is the focus of assessment. Therapists work hard to review all children regularly either by clinic appointments or school visits. The service aims to prescribe to meet fully the needs of individuals more reliant on their wheelchairs, rather than have a 'one size fits all' approach; unfortunately financial limits mean this is at the expense of those clients whose needs for mobility are only occasional. New premises have been a blessing. Purchasing links sadly diminished with the move to PCTs, but a new forward-looking purchaser/provider consortium is expected to bring good news about additional funding to clear current waiting lists.

Sue Atkinson, clinical team leader of the SOUTH DURHAM AND DARLINGTON Wheelchair service based in Darlington, writes: "I am especially grateful to my team for their enthusiasm and willingness to make changes, which have resulted in 100% acknowledgement of all referrals to both the user and the referred to our service within 2 working days. We are working to meet the six opportunities chosen from the Modernisation Agency Wheelchair Service Collaborative. We have a new clinician on secondment at the present time and we hope this will impact on our standard waiting list in the new financial year. However the users of our special seating service have not been compromised due to the current level of funding. We are working closely with other colleagues in the Northern Region to achieve an equitable level of service, and are consulting our Commissioners."

Outreaching initiatives from the HUDDERSFIELD and DEWSBURY Service include a Cushion Protocol developed by Physiotherapist Cary Bernard; a Wheelchair Stability Testing Powered Platform incorporating a Turntable (see following page), and a community-collaborative Wheelchair Transport Guidelines Booklet. In one year around £30,000 is spent on Cushions, so asking Prescribers to operate the Protocol ensures the highest possible standards whilst maintaining good value for money. The Platform, designed in-house by Rehabilitation Engineer, Peter Firth, and built by Repairer Clarke & Partners, with funding from the staff lottery fund, enables the client to experience the feeling of going up/down slopes in safety and without drastic manual handling for the tester. Two local taxi firms met the printing costs for the Booklet, which gives broad guidelines to enable wheelchair-based passengers to travel in safety and comfort whilst giving the transporters useful information. A transport information sheet, to be completed by the user, which gives essential advice to anyone transporting users in a vehicle, is given to each user when their chair is delivered.

# Huddersfield and Dewsbury Wheelchair Service Wheelchair Stability Testing

Stability testing of wheelchairs and occupants has always been a difficult area to address. Testing has been carried out at either 12 degrees, (for attendant pushed chairs) or 16 degrees, (for occupant propelled and electrically powered chairs). The method was to use a small ramp that could be set up to either of the two angles. The chair was pushed on to the ramp by the tester, the brakes applied and the chair was allowed to come to rest, either onto its wheels or into the hands of the tester – whose role then changed from a pusher to a catcher! This was repeated for the other three axis, with the tester again manually pulling/pushing the chair, and occupant into position on the ramp. This posed moving and handling risks for the tester and wheelchair occupant.

The situation is that the chair is to be stable enough to cope with the needs of the client. Some people need a chair that is not very stable; a chair set up like this has increased manoeuvrability and this also facilitates kerb climbing. We felt that there was a need for a piece of equipment that allowed testing of a wide range of different angles, could demonstrate what that angle looks like and feels like to the client AND cut down on the manual handling for the tester.

We checked the "Market" but couldn't find an available product that would meet our needs. The Rehabilitation Engineer Peter Firth came up with a design to build a platform that was low to the ground, and had a variable tilting, powered platform incorporating a turntable. He also included safety straps that were loosely attached to the chair so that it could be tested to its point of instability but not let the chair tip over.

We approached our Approved Repairer, Clarke and Partners, of Sheffield, to see if they would be prepared to manufacture the equipment as a prototype, for us to put it to the test. Working with the Approved Repairer we developed a platform using a powered hoist as the lifting mechanism. This enabled the platform to be very low to the ground, and a car bearing was used as the turntable pivot. The turntable was also made lockable in each of the four axis. An inclinometer was affixed to the platform at "0" degrees.

Funding was sought from and approved by the staff lottery fund to finance the project on the grounds that this equipment would:

- 1) Make testing accurate and meaningful to the client
- 2) Drastically reduce the manual handling for the tester
- 3) Be innovative and improve patient care.

In use the turntable meets all our requirements and enables the client to experience the feeling of going up/down slopes in safety.





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## **Steering Group Membership**

Sam Gallop CBE emPOWER (Chair)

Pamela Marsh
 Department of Health

Peter Gage
 National Wheelchair Services Managers Forum

Rosalind Ham Chartered Society of Physiotherapy

Joe Hennessy OBE
 Joint Committee on Mobility for the Disabled

Ray Hodgkinson British Healthcare Trades Association

Krys Jarvis College of Occupational Therapists

Peter Kemp National Forum of Wheelchair User Groups

Ian Legrand Purchasing and Supply Agency

• Dr Robin Luff British Society of Rehabilitation Medicine

Henry Lumley
 National Wheelchair Services Managers Forum

Carol Morgan The Jennifer Trust

Paul Richardson
 Rehabilitation Engineers Managers Group

Alan Turner-Smith Centre of Rehabilitation Engineering

Alex Winterbone
 National Wheelchair Service Managers Forum

• Aisling Devlin *Em*POWER

Wheelchair Service Mapping Project Manager

# Proposal for the Development of a National Clinical Database of Wheelchair Users

#### Introduction

Estimates of the population of wheelchair users served by the NHS in England vary considerably. The survey carried out by the NHS Purchasing & Supply Agency "IT Systems within NHS Wheelchair Services" looked at 62% of wheelchair services and found a user population of 628,311. Extrapolation from this data would put the total user population at well over 1 million. "Fully Equipped", published by the Audit Commission in 2000, estimated the figure at between 640,000 and 750,000. The disparity of both these estimates illustrates well the problem that there is no reliable data on wheelchair users served by the NHS in England. It is therefore impossible to make sensible forecasts on costs, activity and trends.

It is known that 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 NHS Purchasing and Supplies Agency can provide a national analysis of commercial activity only for wheelchairs.)

Wheelchair provision and the associated activities are administered through at least 150 Centres. The needs of service management and clinical governance require that some form of local database be 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 model 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 ("NASDAB", 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 rational requirements. Commissioning initiatives can be designed and developed on a firm factual basis. There is thus a clear need for a national clinical database describing the wheelchair user population that can quickly and easily produce accurate annual reports.

The diversity of data systems already in use makes it unlikely that a truly national database for the wheelchair using population can be achieved (cf. NASDAB which captures more than 95% of the incidence data). It is therefore proposed that work is funded to produce an agreed minimum dataset for all wheelchair services and from this, further work conducted to produce an interrogative tool specification that can be used to extract anonymised data from all current varieties of wheelchair databases.

The principles of clinical governance include improving standards of care, reducing variation in access to services, improving clinical decision-making and promoting evidence based practice. The last point is particularly pertinent. Would you attempt to run a business with absolutely no information about your customer base?

#### The Approach to the Problem

A demonstration of the feasibility and the potential use of a data collection, collation and analysis method has already been carried out in a project instigated by Dr. Robin Luff at King's College Hospital. This work has been presented at the annual meeting of the Posture

## **APPENDIX 2 (cont.)**

& Mobility Group in both 2002 and 2003. This pilot work covered 7 wheelchair services with a total of 65,000 users.

It is now proposed that funding be sort to allow this initial project to be taken forward at a National level The first stage of this would be to develop an automated technique to interrogate a small number of the other databases used in England. The data from "IT Systems within NHS Wheelchair Services" indicates that working with 4 of the existing systems would cover 60 wheelchair services with a user population of approximately 68%. Development of the tools would allow the specification to be published and other services could, using their own software support facilities, adapt the tools for their own systems and provide increased data.

Item	Task	Man Weeks	Comment
1	Survey, present and decide on the database Systems to be covered.	4	
2	Produce specifications for minimum and enhanced Datasets	8	
3	Produce Data Extraction tools, extraction and communication methods and plan for frequency of data collection.	10	
4	Collation and Analysis of Data	20	60 services would initially need a minimum of a day and a half per service at this development stage
5	Publication of Data (where, what and how)	10	

As can be seen this totals approximately one man-year of work. At the current salary costs for the type of people that would be needed for this work we would anticipate this costing £60,000.

This is the development stage of the project, to take it to the point where the method is validated and data analysis published. It would be anticipated that the project would then go into a maintenance phase and that annual costs would be lower.

http://www.kcl.ac.uk/core

#### **MHRA Guidance**

The MHRA (Devices) aims to prevent adverse incidents happening and, where they have already happened, to prevent them happening again. No device should ever be considered 100% safe and constant effort is therefore required to reduce both the rate at which adverse incidents occur and the severity of the outcome. Reporting incidents to the Agency provides information that may be directly responsible for preventing similar incidents from happening again.

#### Just What is an Adverse Incident?

During 2002 MHRA (Devices) received over 8,700 adverse incident reports covering all types of medical devices. Although approx 2,500 of these were reports concerned with the safety or quality of assistive technology devices such as wheelchairs, artificial limbs, aids for daily living, walking aids, orthoses etc there still appears to be confusion about what should actually be reported. In discussions at various meetings it appears that many of you may not be reporting the risk of or the potential for injury to users, carers or healthcare staff even though many cases of 'near misses' or the potential for reduced safety levels in the future may arise during your work.

In addition to actual harm the **potential** for harm to a user, carer or healthcare staff or others should be reported even though actual harm has not occurred or has been averted by good fortune or the timely intervention of carers or healthcare staff. This **potential** may arise due to:

- shortcomings in the design or manufacture of the device itself;
- inadequate instructions for use;
- inadequate servicing and maintenance;
- locally initiated modifications or adjustments;
- inappropriate user practices (which may in turn result from inadequate training);
- inappropriate management procedures;
- the environment in which a device is used or stored;
- selection of the incorrect device for the purpose

Conditions of use may also give rise to potential:

- environmental conditions (e.g. rain, sun, wind etc);
- location (e.g. devices designed for use indoors may not be suitable for use outdoors or at day centres etc).

The information from adverse incident reports received by MHRA (Devices) helps to build up a picture of what is happening with medical devices across the UK. This is supplemented by reports from around the world. All this information is reviewed to identify trends and, where appropriate, early action is taken on specific problems.

The variety and use of assistive technology is continuing to increase and is not expected to decrease in the near future as the elderly population increases and improvements in healthcare continues to occur. With this background it is surprising to see that during the first 9 months of 2003 there was a reduction in the number of adverse incident reports received by MHRA (Devices).

Is it that assistive technology is becoming safer as the reducing number of adverse incident reports suggests or is it that the **potential** element is not being reported?

If you wish to report it can be done on line via the MHRA web page at <a href="www.mhra.gov.uk">www.mhra.gov.uk</a> or by submitting the details in writing. Guidance on the options available for reporters is given on the web page and within MDA 2003/001.

MHRA (Devices) also issue guidance on the reporting of adverse incidents within the first Medical Device Alert in each year. This year it was MDA/2003/001 and it is available for download from the MHRA web site at <a href="https://www.mhra.gov.uk">www.mhra.gov.uk</a> if you have not already received a copy.

## **APPENDIX 3 (cont.)**

## MHRA Guidance on Wheelchair Stability

MHRA (Devices) continue to receive reports where users and/or carers have been injured or have died as a result of wheelchairs tipping in use.

Approximately 51% of stability related incidents reported to MHRA were concerned with rearwards stability. 39% involved forwards stability and 10% involved sideways stability.

Some investigations show that there is a lack of understanding of the potential effects of the use of wheelchairs on slopes, ramps or uneven ground. Others show a lack of understanding of reduced stability due to the movement of the user or the effects of the addition of accessories or other equipment to the wheelchair.

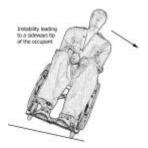


Different body proportions, skeletal deformities or restricted movement of joints of a wheelchair user will also affect stability.

In some cases these issues are further compounded by the effects of the local environment such as lifts, ramps, sloping pavements, dropped kerbs etc and the difficulty for all concerned to equate the usage angles stated in the wheelchair manufacturer's literature into practical terms that a prescriber, user or carer can easily recognise understand and use.

With the ever expanding use of wheelchairs and their accessories combined with other assistive technology such as communication aids, environmental controls, personal computers etc the potential for problems concerning the stability of wheelchairs is unlikely to diminish.

Although the number of adverse incident reports covering real or potential problems is not large, MHRA believes that the far ranging subject would benefit from one guidance document covering all the issues involved. The intention is to give guidance to all concerned including users, purchasers, service providers, prescribers and it aims to highlight areas of risk and provide guidance on reducing or removing these risks whilst maintaining independent mobility for an individual wheelchair user.



A small group of users, manufacturers, service managers, healthcare professionals and MHRA staff has been drawn together and the guidance is now being drafted.

Further drafts will be circulated for wider comment in November/December 2003 and is expected to be finalised for issue in February/March 2004.

ALAN LYNCH Head of MHRA Wheeled Mobility & Seating Centre

#### **TEMPLATE Outcome Measures and Questionnaire**

# Hull and East Riding Community NHS Trust Wheelchair Service

- 1. Improved lifestyle
- 2. Improved indoor mobility
- 3. Improved outdoor mobility
- 4. Safety
- 5. Improved Posture
- 6. Improved comfort
- 7. Carer's needs finding equipment more compatible to carer's needs
- 8. Environment finding equipment more compatible
- 9. Equipment withdrawn
- 10. Advice/information
- 11. Not meeting Criteria
- 12. Pressure Relief
- 13. To aid transfers
- 14. Transport issues
- 15. Equipment compatible for patients needs
- 16. Replacing equipment with same

## **APPENDIX 4 (cont.)**

## **Wheelchair Assessment Review**

Thank you for agreeing to participate in this review of our service. Could you please indicate on this form what change to your life you would like the new equipment to make.

1. I would like to be al	ole to get out more.		
(a) with help	•		D: 1 P
Strongly agree	Agree	Disagree	Strongly disagree
(b) independently	^ ~~~	Discarso	Ctronaly disparce
Strongly agree	Agree	Disagree	Strongly disagree
2 I would like to move	e around indoors more	easily.	
Strongly agree	Agree	Disagree	Strongly disagree
<i>3,</i> 3		•	G. G. G. J. G.
	safer in my equipment.		
Strongly agree	Agree	Disagree	Strongly disagree
4 Lucid like to man	are more easily with m	aquinmant	
	age more easily with my Agree	Disagree	Strongly disagree
Strongly agree	Agree	Disagree	Siluligiy disagree
5. I would like to mana	age more easily with my	v equipment.	
	-	Disagree	Strongly disagree
	•	•	
_	ing posture to improve.		
Strongly agree	Agree	Disagree	Strongly disagree
7 My equinment is dif	fficult to move around r	my home/ work/ social	environment.
Strongly agree		Disagree	Strongly disagree
Oliongly agree	Agioc	Dioagioo	Ollongly Glodg. 22
	er to find the equipmen	-	oush/ lift.
Strongly agree	Agree	Disagree	Strongly disagree
موايده وطنا والتناء	. I tofoundian		
9. I would like advice a		Disease	Other aller dispares
Strongly agree	Agree	Disagree	Strongly disagree
10. I have sore areas	when I sit for periods of	of time. which I would li	ke to improve.
Strongly agree	Agree	Disagree	Strongly disagree
		•	0, 0
	able to transfer from my	-	
Strongly agree	Agree	Disagree	Strongly disagree
42 Lwould like to be :	able to transport my eq	winmont	
Strongly agree	Agree	Disagree	Strongly disagree
Oliongly agree	Agico	Disagree	Olloligly Glodgice
Comments			

Thank you for your time. Please do not hesitate to contact us if you require further information.

## Functioning Everyday with a Wheelchair (FEW)

**DIRECTIONS:** Please answer the following 10 questions by **placing an 'X' in the box under the response** (completely agree, mostly agree, slightly agree, etc.) that best matches your ability to function while in your wheelchair/scooter. All examples may not apply to you, and there may be tasks you perform that are not listed. **Mark each question only one time.** If you answer, \*slightly, \*mostly, or \*completely disagree for any question, please circle the feature(s) (i.e., size, fit, postural support, functional) contributing to your disagreement, and write the reason for your disagreement in the Comments section.

contribu and effic	te to my	<u>ability</u> to <u>ca</u> possible: (	arry out my	daily routine	f my wheelcha es as independe eed to do, am re	<u>ently,</u> safely
Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply
Comments:						
				onal features	s of my wheelc	hair/scooter
			lerance, pain	•		
(e.g., hea			•	•	*Completely Disagree	Does not apply
(e.g., head	Mostly	re, sitting to	lerance, pain	, stability)  *Mostly	*Completely	Does not apply
(e.g., head	Mostly	re, sitting to	lerance, pain	, stability)  *Mostly	*Completely	
Completely Agree  Comments:	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely	apply
(e.g., head completely Agree  Comments:  3. The size match m	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	apply

# **APPENDIX 5 (cont.)**

4. The <u>size, fit, postural support</u> and <u>functional</u> features of my wheelchair/scooter allow me to <u>operate</u> it as independently, safely, and efficiently as possible: (e.g., do what I want it to do when and where I want to do it)								
Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply		
Comments:								
allow me	to reac	h and <u>carry</u>	out tasks at	t different su	s of my wheelc rface heights a .g., table, count	as		
Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply		
Comments:			I					
allow me	e to trans	<u>sfe</u> r from on	e <u>surface</u> to		s of my wheeld rface as indepenair)			
Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply		
Comments:								
7. The size, fit, postural support and functional features of my wheelchair/scooter allow me to carry out personal care tasks as independently, safely, and efficiently as possible: (e.g., dressing, bowel/bladder care, eating, hygiene)								
Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply		

## **APPENDIX 5 (cont.)**

8. The size, fit, postural support and functional features of my wheelchair/scooter allow me to get around indoors as independently, safely, and efficiently as possible: (e.g., home, work, mall, restaurants, ramps, obstacles)								
Completely	Mostly	Slightly	*Slightly	*Mostly	*Completely	Does not		
Agree	Agree	Agree	Disagree	Disagree	Disagree	apply		
Comments:								
Commonto.								

9. The <u>size, fit, postural support</u> and <u>functional</u> features of my wheelchair/scooter allow me to <u>get around outdoors</u> as independently, safely, and efficiently as <b>possible:</b> (e.g., uneven surfaces, dirt, grass, gravel, ramps, obstacles)								
Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply		
Comments:								

10. The <u>size, fit, postural support</u> and <u>functional</u> features of my wheelchair/scooter allow me to <u>use personal or public transportation</u> as independently, safely, and <u>efficiently as possible:</u> (e.g., secure, stow, ride)								
Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply		
Comments:								

#### For questions 2 to 10:

size (e.g., wheelchair and seating frame - width, length, height)

fit (e.g., not too large, not too small, allows desired movement)

**postural support** (e.g., provides support, stability, and control for the body-bones, muscles, and tissues)

**functional** (e.g., speed, wheels, cushion, controller, backrest, legrests, seat belt, tilt/recline system, seat elevator, laptray, basket, cane holder, horn, lights).

emPOWER, courtesy of ©Holm, Mills, Schmeler, & Trefler, 2003

# The Relevance of Wheelchair Provision to the National Service Framework for Older People

The National Service Framework for Older People sets out eight standards promoting older people's good health and independence, highlighting the fact that older people are the main users of health and social care services. The majority of Wheelchair Users in England are over the age of 60. This discussion Note draws attention to the relevance of effective and timely wheelchair provision for the achievement of the Standards, and thereby requests increasing focus on such provision.

#### Standard One: Rooting out age discrimination

NHS services will be provided, regardless of age, on the basis of clinical need alone. Social care services will not use age in their eligibility criteria or policies, to restrict access to available services.

There is no evidence of institutionalised discrimination in the provision of standard wheelchair services. There are however indications that discrimination on the basis of age is endemic in many areas of health and social care effected by budgetary strands and decisions and personal attitudes.

Does the lack of specific legislation mean that staff give lower priority to older people's needs compared with avoiding discrimination where there are statutory obligations e.g. race and gender

Is there adequate "awareness" training?

It is suggested that there should be appraisal to ensure that for "special" seating services older people are given the same priority as children and other younger clients.

#### Standard Two: Person-centred care

NHS and social services treat older people as individuals and enable them to make choices about their own care. This is achieved through the single assessment process, integrated commissioning arrangements and integrated provision of services, including community equipment and continence services.

It is for discussion whether, despite the excellent ICES developments, older people with complex disabilities, can have their specialist wheelchair and other requirements met, and sustained, through a single assessment process, unless they have accessible to them a Centre of Excellence for Rehabilitation, which can appraise and respond to all the complex needs.

Do the existing services/mechanisms have sufficient resources to enable them to respond in a timely and effective manner?

#### Standard Three: Intermediate care

Older people will have access to a new range of intermediate care services at home or in designated care settings, to promote their independence by providing enhanced services from the NHS and councils to prevent unnecessary hospital admission and effective rehabilitation services to enable early discharge from hospital and to prevent premature or unnecessary admission to long-term residential care.

An elderly person, who requires a wheelchair on discharge from hospital, cannot be discharged without it. If it is not possible to acquire a wheelchair, the elderly person's stay in hospital is extended. Ensuring ready availability of individually suitable wheelchairs for the discharge/rehabilitation process thus prevents "bed-blocking".

Do the existing services/mechanisms have the necessary resources to enable them to respond in a timely and effective manner?

## **APPENDIX 6 (cont.)**

#### Standard Four: General Hospital Care

Older people's care in hospital is delivered through appropriate specialist care and by hospital staff who have the right set of skills to meet their needs.

In order to achieve maximum benefit from having been in hospital it is important that the rehabilitation process meets individual user and carer needs. As previously discussed, an appropriate wheelchair will lower the chances of readmission to hospital and also benefit the carer who may be elderly and frail. In this case specific wheelchair equipment should be looked at i.e. lightweight or powered to cater for an elderly carer who would have difficulty pushing, or in pushing safely, a standard wheelchair.

#### **Standard Five: Stroke**

The NHS will take action to prevent strokes, working in partnership with other agencies where appropriate.

People who are thought to have had a stroke have access to diagnostic services, are treated appropriately by a specialist stroke service, and subsequently, with their carers, participate in a multidisciplinary programme of secondary prevention and rehabilitation.

Two of the main components for the development of integrated stroke services are early and continuing rehabilitation, and long-term support, for the stroke patient and their carers. Many of the 110,000 people who have a stroke each year will require a wheelchair.

What links exist locally that bring together the stroke and the wheelchair services?

#### **Standard Six: Falls**

The NHS, working in partnership with councils, takes action to prevent falls and reduce resultant fractures or other injuries in their populations of older people.

Older people who have fallen receive effective treatment and, with their carers, receive advice on prevention through a specialised falls service.

Following a fall, an elderly person may need a wheelchair during the rehabilitation process, or perhaps for long-term use. This Standard also applies in the event where an elderly person may be supplied with a wheelchair as a preventative measure if they are at risk of falling. A wheelchair, which could prevent falls by elderly persons not as safely mobile as they once were, avoids admission to hospital in the first instance.

What links exist locally that bring together the falls and the wheelchair services?

#### Standard Seven: Mental Health in older people

Older people who have mental health problems have access to integrated mental health services, provided by the NHS and councils to ensure effective diagnosis, treatment and support, for them and their carers.

It is essential that, where mental health is involved, safety aspects are fully addressed to facilitate maximum possible wheelchair provision and independence.

Standard Eight: The promotion of health and active life in older age
The health and well-being of older people is promoted through a co-ordinated programme of action led by the NHS with support from councils.

Mobility, in the home and in the community, is essential to the promotion of health and active life. An EPIOC for instance can transform and promote the active life and physical and mental well-being outreach of an older person, both in the home and in the community. Audit Commission reports demonstrate that present provision is budget not needs led, and that there is insufficient funding.