



**Associate Parliamentary Group for Limb Loss
All-Party Parliamentary Group for Spinal Cord Injury
All-Party Parliamentary Group for Muscular Dystrophy**

Helping to emPOWER

PATIENT LED WHEELCHAIR & SPECIAL SEATING SERVICES

with the support of this

PATIENTS CHARTER

throughout

**ENGLAND, SCOTLAND, WALES,
NORTHERN IRELAND**

“Together we can move towards a modern wheelchair service which better meets the needs of its users and supports them in leading more independent lives.”

The Baroness Wilkins

FOREWORD

It is estimated that there are 1.5 m wheelchair and special seating Users throughout the United Kingdom¹. Some 1.2 million are regular Users of the four National Health Services – with still more needing to use each Service for a time limited period only.

The National Prosthetic and Wheelchair Services Report 1993-1996 advised that many of the difficulties experienced by wheelchair Users and Providers were due to low funding levels and limited resources.

In 2000 the Audit Commission published *Fully Equipped* and one of the specific recommendations was the introduction of incremental improvements to wheelchair services. Their subsequent report *“Fully Equipped 2002 – Assisting Independence* revealed that progress had been patchy. “The UK lacks a national focus for services designed to support independence.” (www.audit-commission.gov.uk)

“National Clinical Guidelines for Specialised Wheelchair Seating” published by the British Society of Rehabilitation Medici in 2004 remind us that people who need specialised seating usually also require help with posture through out the day and night..(www.bsrm.co.uk)

The emPOWER “NHS Wheelchair and Seating Services Mapping Project” in 2004 demonstrated how staff, despite changing organisational environments outside their influence, remain determined to “go the extra mile to provide services which feel personal within a framework of equity and good use of public money.” (www.apllg.eu)

The Specialised Services National Definition Set No. 5 (3rd Edition) published in 2009 reports the effectiveness, of the hub and spoke model for specialised services, and of the multi-disciplinary team. (www.dh.gov.uk)

The NATIONAL WHEELCHAIR MANAGERS FORUM has commendably and collaboratively published and updated comprehensive National Management Standards (www.wheelchairmanagers.nhs.uk).

Over the years and currently, numerous Charity reports have drawn attention to significant unmet needs which the Charities are doing their best to meet, innovatively, fund-raisingly, and with high standards. The Charities willingly share their specialist knowledge of particular conditions and seek in difficult times to continue to provide collaboratively their financial and services support. Examples include: Whizz-Kidz www.whizz-kidz.org.uk; Muscular Dystrophy Campaign www.muscular-dystrophy.org; Spinal Injuries Association www.spinal.co.uk .

A PARTNERSHIP

In publishing this Charter for and by Users of Wheelchairs, we understand that to communicate effectively, we must concentrate on salient points; every fine detail cannot be covered. This Charter brings with it an obligation on Users and on Carers to collaborate reasonably, and in a non-discriminatory manner, with all those professional staff at each Wheelchair Service Centre who provide the skilled services which enable us to achieve and maintain our maximum personal independence. . A Conciliation Office should be available for each site to which either the Patient or the member of Staff or Both may refer any irresolvable difficulties.

The correct supply, care and use of a Wheelchair depend significantly on the shared co-operation of each User in his/her on-going treatment and rehabilitation programme. Our four National Health Services are each a Partnership. In particular Users should:

- keep appointments or advise their Centre when this is impossible
- properly care for and maintain equipment, and
- promptly advise their Centre of wear and tear, and
- thereby avoid undue emergencies.

Throughout this Charter the expression "User" implies "User & Carer", where appropriate. The role of the Carer may be, and often is, as vital as that of the User.

MODERN AND DEPENDABLE SERVICES

This Charter supports the provision of the highest quality of orthotic, prosthetic, wheelchairs & special seating, and other vital assistive services/technologies as set out in SPECIALISED SERVICES NATIONAL DEFINITIONS SET NUMBER 5 for all PERSONS WITH COMPLEX PHYSICAL DISABILITIES.

This Charter supports:

- Enhancing Quality of Life for People with Long Term Conditions
- Helping People to recover from episodes of ill health or following injury.

This Charter supports the continuing development and sustenance of Modern and Dependable National Health Wheelchair & Special Seating Services, and of the well-being of all staff who work in them. Users seek to help:

- raise standards
- abolish waste and unnecessary bureaucracy
- break down barriers between health, social care, education and employment
- guarantee equality, quality, excellence and efficiency
- share best practices openly for the benefit of all
- create and nourish Centres of Excellence.

QUALITY OF CARE

The User assesses Quality of Care by its **Effectiveness** – the extent to which, and the quality with which, his/her needs and expectations are met. Effectiveness requires Services to be organised and managed around Patient and Carer needs and to deliver maximum possible health and independence for both adult and child patients.

Health Professionals should, subject to health and safety requirements, advise the User of the optimum solutions to his/her needs. Such advice should not be compromised by resource constraints, although regard must be had in the short-term to any such constraints.

The only eligibility criteria must be the clinical, lifestyle and culturally appropriate needs of each individual Adult Service User or Child Service User and their Carers and Families. Prescriptions must avoid discrimination.

10 C's

To meet User needs for Posture and Wheeled Mobility and to promote high standards of service delivery, Services must meet all of the following 10Cs, adopted by the Associate Parliamentary Limb Loss Group (www.apllg.eu):

Comfort

Equipment must provide adequate postural support and accurate fit, particularly at the interfaces with the skin, to enable the Patient to achieve optimal pain-free mobility and dexterity, and to avoid tissue

breakdown and pressure sores. Staff must be given additional training in the needs of Children and of Older People in all environments.

Choice

Users need to be able to choose from a variety of convenient high-quality Providers, with clear and consistent information and advice to back that Choice, with money following the User, and Staff having freedom to meet Users' expectations – the location of fitting needs to be convenient with a choice of appointment time to meet the needs of an adult User and any carer or a child User and his/her parents/carers – all children with a need at birth for Special Seating should be referred to a Specialist within the first month of life, and assumptions should not be made that a child will not be suited to the fitting of such support devices;

Capability

Equipment must be appropriate to each User's requirements, mechanically safe, easily maintained and easy to use – instructions must be given which are suitable for and understandable by children wherever possible as well as their parents – there should be a single point of contact for advice about maintenance/recreation/travel/safety etc;

Cosmesis

Where necessary for self-esteem, Equipment must be cosmetically acceptable commensurate with optimal function – needs of children and of young people, at the early stages of developing a positive self-image, must be met;

Competence

All Healthcare Professionals whether from the NHS, Contractors to the NHS, or the Voluntary sectors, must (be enabled to) have the appropriate educational and career opportunities in order further to develop and to sustain their competencies and skills – Staff should be specially trained in dealing with both disabled adult's and disabled children's needs;

Capacity

Budgets must provide adequate Capacity for cost-effective and patient-effective services and for long-term adequate workforce planning and recruitment;

Consultation

Users and Carers must be Equal Partners with Professionals in the planning and the operation of services;

Consistency

Services delivered must not vary with location except where explicable by clinical variables;

Calibration

Key performance indicators must calibrate the degree to which services improve health and social outcomes for individuals and for populations;

Caring

Caring is the Catalyst, respecting dignity and privacy, throughout the entire User pathway – it is especially important to reassess growing children every 3-6 months to make sure that they always have optimal comfort and performance from their Equipment.

(Users may require other Assistive Technologies such as Orthoses and Prostheses and these Criteria apply throughout.).

THE 'DUTY TO INVOLVE'

Legislation which came into force in 2003 placed a duty on certain NHS organisations to involve and consult when it came to making changes to services. NHS Managers have not always been clear when they have to involve and how best to do this. The changes to the law introduced by the Local Government and Public Involvement in Health Act 2007 make this clearer.

The strengthened 'duty to involve' came into force on 3 November 2008. In summary, the duty requires Managers to involve users of services in:

- Planning and provision of services;
- Development & consideration of proposals for changes in the way services are provided;
- Decisions affecting the operation of services.

THE NHS CONSTITUTION

In England, the Government has published the NHS Constitution, setting out the principles, values and rights that guide the NHS in England. These principles and rights include a commitment by the NHS to the highest standards of excellence and professionalism in the care you receive and the right to be involved in discussions and decisions about your healthcare.

The NHS Constitution was produced to inform people of what they should expect whenever they use NHS services. As a reference point, the Government intends for people to compare the services they receive with what is written in the Constitution and to highlight any cases where the standards it describes are not being met. Similarly, it will act as a basis for how local healthcare providers operate. Anyone providing NHS services will be required by law to "take account" of the Constitution in the planning and delivery of services.

The NHS Constitution states that ***"you have the right to be involved, directly or indirectly, in the planning of healthcare services, the development and consideration of proposals for changes in the way those series are provided, and in decisions to be made affecting the operations of those services."***

VALUE FOR MONEY

Patients welcome the shared recognition through this Charter that Patient-Centred Commissioning generates Value for Money. Patient-centred treatment and care, as well as improving the Quality of Life of the Patient and the job satisfaction of Health Professionals, also produces the best possible outcomes and lower overhead costs and lower per-case costs and shorter hospital stays and sustained rehabilitation outside hospital settings.

UN CONVENTION ON RIGHTS OF PERSONS WITH DISABILITIES

Relevant Rights within the United Nations Convention on the Rights of Persons with Disabilities must apply, including those Rights listed in APPENDIX A, which is an integral part of this Charter.

INDEPENDENCE FOR LIFE

Needs change over time, through at least 'seven stages', from the new-born babe to the senior citizen. To foster Independence for Life, and to avoid crises, each User should be entitled when his/her needs change to request review by his/her clinical rehabilitation team. Adequate time and skilled resources must be

available for the learning of new skills, and the provision of new or redesigned equipment. There should be one named focal point of contact for the user, enhanced in cross-boundary situations by flexible sharing of funding across budgetary and organisational boundaries.

The User should have easy access to beneficial equipment, treatments, therapies, and services, and full and up-to-date information about new equipment and technology, including access to manufacturers' catalogues at each Centre.

The User has first-hand knowledge of his/her requirements for independence in day-to-day living, and needs assurances that his/her views will be taken into account.

The Occupational Therapist, the Physiotherapist the Rehabilitation Engineer and the Clinical Technologist, in consultation with other members of the Rehabilitation Team, are the lead experts in matching design, production and delivery with User requirements. Their views should be taken collaboratively into account.

GOALS & PROMS

Collaborative, realistic, and attainable Goals must be set and agreed. The patient cannot decide /demand these independently. In some instances other Assistive Technologies, may need to be included in the appropriate Prescription. Groups and Individual Patients should take a supportive interest in, and should be enabled to share in, the development and application of, *Patient Related Outcome Measures* (PROMS).

PRESCRIPTION

Prescription must be undertaken by an appropriately qualified Health Professional, who may be working individually or within a team setting. Simple provision of treatment may be undertaken by a Technician working within agreed protocols of care under the direction of the Health Professional, with clear lines of responsibility and oversight in place. Each Prescription should be individually formulated to suit the User's rights and needs and lifestyle and goals. If, because of lack of funding or pressure on resources, the most appropriate solution cannot be provided, the reasons must be fully documented by the Health Professional in a written Report of Prescription and circulated to all concerned.

SERVING PERSONNEL AND VETERANS

Veterans are guaranteed by Government priority for service-attributable out-patient and in-patient treatment. They are entitled to reimbursement by their National Health Service Centre of travel expenses and any loss of earnings. Government guarantees include:

- The standard of provision to injured personnel by the Defence Medical Services will as a minimum be matched post-service by the National Health Services in Great Britain.
- We will raise awareness with healthcare professionals – including drawing attention to priority treatment for Veterans with Service-attributable conditions.

COMMISSIONERS

Post-code lotteries - sadly despite the best endeavours of all concerned to see their removal – continue. The quality of your service may vary according to where you live. Choice is illusory when you cannot easily travel beyond your local Centre.

This Charter supports effective commissioning by further sharing knowledge about high quality clinical outcomes so that:

- the right patient (clear patient selection criteria and referral guidelines) is offered

- the right treatment (evidence based, clinically and cost effective interventions, in the appropriate setting) by
- the right provider (monitored against agreed service/clinical quality standards) in
- the right place (optimising geographical access but avoiding unnecessary duplication of provision)
- at the right cost (robust costing and information systems and demonstrable value for money)
- with the right-full involvement of the patient (adequate information to enable supported choice).

PROVIDERS

Every Provider with his/her Commissioner should promote, for new and for existing Contractors, equitable competitive opportunities in a viable commercial climate, in which quality of service is encouraged and rewarded. The Contractor should respond accordingly. In awarding Contracts there must be due regard to quality and outcomes as well as to prices. There should be a national template for invitations to tender, to foster fair competition, and to reduce wasteful tender costs.

Every Provider must enable the User and Professional Staff to benefit from continuity of relationships. Excessive staff turnover is an indicator of bad management and/or inequitable terms and conditions of employment. Both User and Staff need time to get to know each other and to continue to develop mutually optimum solutions as the User's needs change. Where possible (and where there is more than one Therapist), the User's ability to choose his/her Occupational Therapist or Physiotherapist should be respected. Every effort should be made to secure continuity of care.

Where required to meet the User's needs for specialist services promptly and comprehensively, it should be seen as commendable management practice for funding to follow the User, and to cross organisational boundaries swiftly and without undue bureaucracy.

A nation-wide listing of the wheelchair services and of types of wheelchair on general issue (including those under the voucher scheme partnership option) should be published annually by each National Health Service.

CONSULTATION WITH USERS AT EACH SERVICE CENTRE

Management at each Service Centre should proactively and continuously facilitate, within the Centre's arrangements for total Consultation, the forming and sustaining of a User-Led Group by the provision of publicity, accommodation, travel/carer support and secretarial services. Each such Group will proactively and continuously and courteously collaborate with Management. As required by law, Consultations must be real and not just procedural. A Key Action is to *"Find ways of involving patients and their carers in planning services."*

The foundation stone of effective consultation is the Centre's ANNUAL BUDGET and INCOMES/EXPENDITURES outcomes. Each Centre should publish annually to its User Group its Business Plan.

INFORMATION

Each Centre should publish widely, by non-discriminatory means and in accessible formats, information about the services and facilities it provides, and the benefits and services provided by other relevant agencies, as well as information about the standard NHS complaints procedures and means of expressing appreciation and praise.

CONTINUED PROFESSIONAL DEVELOPMENT

Invitations to tender and service agreements should provide for and show transparently “Continued Professional Development Requirements” for all staff. Delivering the workforce skills to meet User rights and needs requires, for all Allied Health Professionals, sustained opportunities for Continued Professional Development, and clear career “stepping stones”.

Undergraduate and Postgraduate studies and training need to be accessible regardless of distance both geographically and academically. Workforce planning and practice must facilitate:

- Involvement of Therapists, Rehabilitation Engineers, and Clinical Scientists in clinical/planning responsibilities and requisite post-graduate training leading to the appointments nationally of Consultant Practitioners;
- Opportunities for Technicians to qualify for and to achieve appointments as Consultant Technicians or the relevant ISPO Category and to take Foundation Degrees;
- Opportunities for Administrators further to enhance their Management skills and achieve additional responsibilities.

RESEARCH AND DEVELOPMENT

Invitations to tender and service agreements should provide for and show transparently Research and Development requirements and percentage of total allocated funding. Resultant best practices should be shared nationally through the Knowledge Sharing Network for People with Complex Physical Disabilities. Staff should be enabled to introduce Innovations in technology and in practice with minimum delay. Beneficial developments and knowledge achieved locally should be made available to patients nationally. Listening to Patients and seeking their views will ensure that problems seek solutions and not vice-versa.

NOT A BLUEPRINT

This Charter is a pathway partnership to sharing improvements and best practices – not a blueprint for how services should be delivered. It recognises the need for mutual respect and support among users/families/carers, and the providers of services whose skills and commitment are essential to maintaining the right mix of incentives, transparency, plurality of providers, specialised commissioning, practice-based commissioning and patient choice and consultation.

APPENDIX A (which is an integral part of this Charter)

Extracts from the United Nations General Assembly Convention on the Rights of a Person with Disabilities, Resolution number 61/106 dated 24th January 2007. For a full copy of this convention see <http://www.un-documents.net/a61r106.htm>

Article 3 - General Principles

The principles of the present Convention shall be:

- a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- b) Non-discrimination;
- c) Full and effective participation and inclusion in society;
- d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- e) Equality of opportunity;
- f) Accessibility;
- g) Equality between men and women;
- h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Article 9 - Accessibility

1. To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:
 - a) Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;
 - b) Information, communications and other services, including electronic services and emergency services.
2. States Parties shall also take appropriate measures:
 - a) To develop, promulgate and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public;
 - b) To ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities;
 - c) To provide training for stakeholders on accessibility issues facing persons with disabilities;
 - d) To provide in buildings and other facilities open to the public signage in Braille and in easy to read and understand forms;
 - e) To provide forms of live assistance and intermediaries, including guides, readers and professional sign language interpreters, to facilitate accessibility to buildings and other facilities open to the public;
 - f) To promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information;

- g) To promote access for persons with disabilities to new information and communications technologies and systems, including the Internet;
- h) To promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost.

Article 17 - Protecting the integrity of the person

Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.

Article 19 - Living independently and being included in the community

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Article 20 - Personal mobility

States Parties shall take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities, including by:

- a) Facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost;
- b) Facilitating access by persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost;
- c) Providing training in mobility skills to persons with disabilities and to specialist staff working with persons with disabilities;
- d) Encouraging entities that produce mobility aids, devices and assistive technologies to take into account all aspects of mobility for persons with disabilities.

Article 25 - Health

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

- a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;
- b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
- c) Provide these health services as close as possible to people's own communities, including in rural areas;
- d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;
- e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
- f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

Article 26 - Habilitation and rehabilitation

1. States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:
 - a) Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;
 - b) Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.

2. States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.

3. States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.