

Specialised Wheelchair Seating National Clinical Guidelines

A report by a multidisciplinary expert group commissioned by the British Society of Rehabilitation Medicine

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Chair: Dr Linda Marks

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Specialised Wheelchair Seating National Clinical Guidelines

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A publication such as this can only be achieved by teamwork.

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1. Introduction

- 1.1 Specialised wheelchair seating is needed by people who require a wheelchair for mobility, but due to instability or deformity, need additional support in order to function.
- 1.2 These guidelines have been commissioned by the British Society of Rehabilitation Medicine (BSRM) because specialised wheelchair seating is poorly understood and yet would appear to benefit an increasing number of people. Whilst services have traditionally been focused on the needs of children, there is an expanding cohort of adults surviving and living with profound complex disability for whom the service is equally necessary.
- 1.3 The National Service Framework (NSF) for Children's services (Part 1–2003) and the NSF for Long term conditions (expected 2004) are currently under development, and will inform future service configuration. The existing specialised seating services are limited, and therefore if new services are to be established, a framework for optimum practice at least provides a benchmark for these developments.
- 1.4 The Clinical Effectiveness and Evaluation Unit (CEEU) of the Royal College of Physicians (RCP) utilises the AGREE Appraisal Tool 2 for the assessment of clinical guidelines. This set of National Clinical Guidelines for Specialised Wheelchair Seating has been developed in accordance with these principles, as described in Section 2.

Introduction

2. The process of guideline development for specialised wheelchair seating

Scope and purpose

Overall objective of the guidelines

- 2.1 To improve the clinical care and ongoing support delivered to disabled people who require specialised wheelchair seating.
- 2.2 To improve the understanding of specialised seating and the potential benefits that it can impart.
- 2.3 To stimulate further research in this area in order to provide the evidence base for further expansion of these services.

Target audience

- 2.4 These guidelines are targeted towards the range of people involved in the process of specialised seating provision, including:
 - Doctors, allied health professionals and engineers involved in the assessment and care of people who need this service.
 - Commissioners and managers of these services.
 - Voluntary and charitable organisations that work with these services.
 - Manufacturers who supply the equipment prescribed by these services.
- 2.5 We would also hope that these guidelines contain useful information for clients of these services, their families, carers and friends.

The client group covered by the guidelines

2.6 People of all ages, who require a wheelchair for mobility, but who also need additional support due to postural instability or musculoskeletal deformity. The guidelines also address the needs of the families/carers of these disabled people.

Scope

- 2.7 These guidelines cover the assessment, prescription, delivery and review of specialised wheelchair seating and also the information and advice provided to the disabled person and their carers.
- 2.8 The guidelines do not give specific advice on which system to use in a particular clinical situation since this will depend on a complex interaction between the individual's needs in the context of their environment.
- 2.9 People who need specialised wheelchair seating usually also require help with posture throughout the day and night (24-hour postural management) not only for sitting but also for lying and standing (if applicable). At the current time, these guidelines focus on the seating aspects only.
- 2.10 Whilst these guidelines allude to certain financial aspects of providing a specialised wheelchair seating service, no attempt has been made to cost optimum service provision. It was felt that this is a commissioning issue and outside the direct remit of the document.

The guideline development group

- 2.11 A guideline development group (the Expert group) involved wheelchair users, doctors, therapists, and engineers, (see Appendix 5).
 - Additionally the guidelines were circulated for wide consensus amongst members of the BSRM (British Society of Rehabilitation Medicine) and the PMG (Posture and Mobility Group). Ninety-four initial requests (representing eighty-nine individuals/teams) resulted in thirty-seven returned comments.
 - The list of organisations who collaborated in the development of the guidelines is shown in Appendix 6.
 - Elements of the guidelines were also presented at various national and international meetings and feedback received was used to refine the content.

Editorial independence

- 2.12 Competing interests for members of the expert group were fully declared and are listed in Appendix 5.
- 2.13 These guidelines were commissioned by the BSRM but there were no external funding sources.

Evidence to support the guidelines

- 2.14 Guideline development was preceded by a systematic review of the literature, which is published separately. The literature search was performed through the British Medical Association Ovid Online service using the following keywords:
 - 1. Wheelchair and/or wheelchair.mp
 - 2. Posture and/or posture.mp
 - 3. Kyphosis and/or kyphosis.mp
 - 4. Seat/
 - 5. 2 or 3 or 4
 - 6. 1 and 5
- 2.15 References from EMBASE 1980 October 2002 (n=218), Medline 1966 October 2002 (n=251) and CINAHL 1982 October 2002 (n=60) were pooled and duplicates eliminated. A preliminary interrogation of the titles and electronic abstracts was performed by hand to select articles suitable for this review. Relevant references listed in the review articles, but not identified in the search were also obtained. This original search was repeated in October 2003. In addition, the College of Occupational Therapists (COT) did a further search of CINAHL, AMED and HMIC from 1997-2003 as well as checking their own specialist sources from within the COT library. Finally, authoritative previously published professional society reports and personal communications from recognised experts were included.
- 2.16 A total of 472 studies were identified in this way of which 65 were considered relevant to these guidelines. As these guidelines concentrate on the process of provision of specialised wheelchair seating, only references specific to this area were included. Formal consensus techniques were used to formulate the recommendations.
- 2.17 Evidence is linked explicitly to the guideline statements using the following classification, which is currently used by the Royal College of Physicians, and in other published guidelines³.

Level of evidence	Type of evidence	Grade of recommendation
Ia	Meta- analysis of randomised controlled trials RCTs)	А
Ib	At least one RCT	А
IIa	At least one well-designed controlled study, but without randomisation	В
IIb	At least one well-designed quasi-experimental design	В
III	At least one non-experimental descriptive study (e.g. comparative, correlation or case study)	В
IV	Expert committee reports, opinions and/or experience of respected authorities	С

Levels of evidence

- 2.18 Research in the field of specialised wheelchair seating is scant and the reasons for this are:
 - The relatively short period of time that the sub-specialty has existed.
 - It is impossible to blind the patient or the clinician to the presence or absence of a seating intervention.
 - Current therapeutic practice has probably reached the stage where it would be unethical to deny a patient appropriate postural equipment under trial conditions.
- 2.19 Additionally there is no agreed definition for specialised seating and there is further confusion and inconsistency about terminology used in clinical practice.
- 2.20 The guidelines therefore rely almost exclusively on expert opinion and case studies, generating a very weak strength of evidence and rarely any grade of recommendation above a 'C'. There are very few existing documents or guidelines in this field, and those that have been published deal with the totality of wheelchair services, without much specific detail on specialised wheelchair seating^{4,5,6}. Where such documents were known to the expert group, they have been referenced in the usual way.

Implementation and cost implications

2.21 We hope that these guidelines will improve the quality of care currently being provided to people who use specialised wheelchair seating. However, further services will be required if the current patterns of survival of illness/trauma continue. These services are high cost and low volume, and whilst the formal evidence of their efficacy is scant, the hidden costs of inaccurate provision/lack of provision e.g. dependency, hospitalisation or surgery for complications, are significant.

Updating and review

- 2.22 Guidelines are continuously being developed, and this area of practice is evolving and expanding in response to demand. The evidence base to support specialised seating service provision is urgently required and would benefit from structured research programmes supported by academic institutions.
- 2.23 These guidelines will be reviewed and updated at regular intervals (5 years) by the BSRM, subject to the availability of funding.

Terminology

- 2.24 For the purpose of these guidelines, the terms "client or disabled person/child" have usually been used to describe the users of this service. This is because people/children who use a wheelchair and specialised seat for their mobility and function, are primarily accessing these services for the appropriate technology to assist them. Whilst there may be medical connotations to this provision, they are not seeking the medical form of treatment that might be understood from the term "patient".
- 2.25 We hope that the definitions that have been developed during the process of writing these guidelines, may help to clarify understanding in the field of specialised wheelchair seating.

Tools for application

- 2.26 The guidelines are accompanied by some suggested tools for application including:
 - Check lists for technical factors to be taken into account in prescribing specialised wheelchair seating system and for clinical reviews and reassessments.
 - Client pre-appointment information sheet.
 - Suggested template proforma for specialised wheelchair seating assessment and risk assessment.

3. Background

"What the user wants"

3.1 "Imagine spending 18 hours a day in the same pair of shoes; the same pair for the house, for going shopping, for walking the dog. Imagine if those shoes were for a growing child; you would of course ensure that they fitted well, were comfortable, preferably aesthetically appealing and ideally you'd have a choice. You would also of course ensure that as the child grew, the shoes still met those criteria! As a parent of a child with severe physical disabilities the need for expertly fitted special seating is vital. My daughter Sarah more than anything needs to be comfortable so that she can actually endure long spells in her chair; she needs to be seated well so that we can attempt to prevent deformities (which means less time spent in hospitals having corrective surgery). She needs to be able to access equipment to help her interact with the environment and socialise with her friends. She needs people to remember that she is a person with feelings, not a statistic or a cost implication."

Mother of an 18yr old who is dependent on specialised wheelchair seating.

- 3.2 A solution to the disabled person's needs can only be met by comprehensive assessment of the specific postural problems set within the context of functional ability and lifestyle⁷. This may require consideration of other equipment that is already in use such as environmental controls, communication aids, etc.
- 3.3 People who need specialised wheelchair seating usually also require help with posture throughout the day and night (24-hour postural management)^{8, 9} not only for sitting but also for lying and standing (if applicable). At the current time, these guidelines focus on the seating aspects only.

Evidence for effectiveness of specialised wheelchair seating

- 3.4 There is published evidence that specialised wheelchair seating contributes to:
 - Reduction in hip subluxation¹⁰
 - Fewer pressure sores^{11, 12}
 - Improved upper limb function¹³⁻¹⁵
 - Improvements in respiration¹⁶ and feeding¹⁷
 - Improved personal interaction¹⁸⁻²¹
 - Better opportunities in education and employment^{22, 23}.
- 3.5 In addition there is anecdotal evidence to suggest that specialised wheelchair seating also contributes to comfort, dignity and psychological well being²⁴.

What is specialised wheelchair seating?

- 3.6 People with a permanent disability, which limits their ability to walk, are eligible for NHS wheelchair provision. Specialised wheelchair seating is required by those who need a wheelchair for their mobility but due to postural instability or deformity need extra support in order to function.
- 3.7 Specialised wheelchair seating is a term that describes a number of postural systems or components, which are designed to be used in a wheelchair base to optimise the disabled person's ability to function.

Background

- 3.8 A specialised wheelchair seating service encompasses holistic assessment of the disabled person including disabled children²⁵ in the context of their life-style and aspirations including postural advice, which may or may not require equipment provision.
- 3.9 In the event of equipment being prescribed, education and dissemination of information on optimum use is an integral component.

Provision of specialised wheelchair seating

- 3.10 Specialised wheelchair seating was hardly mentioned in rehabilitation circles in the UK until the mid-1980s²⁶ but the need was recognised in North America approximately 10 years earlier²⁷.
- 3.11 Provision of specialised wheelchair seating is a complex process involving analysis of posture and function in relation to life-style and potential aspirations²⁸⁻³⁰. With easy access to the Internet and aggressive marketing from the manufacturers, the disabled person and the carers frequently come across attractive looking specialised wheelchair seating systems as possible solutions to their postural and functional requirements. However, without an independent source of advice, these systems could prove to be inappropriate if not harmful^{18, 31, 32}.

The process of provision includes:

- Assessment: holistic assessment of the disabled person and his/her needs including access to medical and surgical aspects of the individual's care¹⁹
- **Prescription**: prescription of the specialised wheelchair seating with optimal configuration³¹
- Fitting and delivery: supplying the equipment: ordering, manufacture, fitting and delivery.
- Information, education and training for the disabled person and the carers to facilitate appropriate use for maximum benefit
- Liaison with other agencies: social, educational, voluntary and charitable

Followed by:

- Monitoring to ensure successful provision
- Maintenance and repair
- **Reviews and reassessments** for growth or changing needs^{31, 33}
- 3.12 Thus most disabled people who require specialised wheelchair seating remain in a continuum of care, punctuated by specific episodes of intervention³⁰. Freney et al²⁸ reported that the average seating system would need replacing every 2 to 3 years and Fife et al³⁴ reported replacement of seating system every 2 to 4 years. Internal audit data from a large specialised wheelchair seating service showed that on average the seat needs replacing every 4 years (range 2-9 yrs)³⁵.

Who needs specialised wheelchair seating?

- 3.13 There is published data regarding specialised wheelchair seating provision (i.e.who gets it), which does not necessarily equate with who needs it. Significant financial constraints at the current time have led to a level of unmet need, which has yet to be quantified.
- 3.14 Bar³⁶ indicated that approximately 10% of wheelchair users required some form of postural support but this included pressure relieving cushions. Historically children have dominated the client profile^{27, 37, 38}, but their needs as adults and the requirement of adults with disabilities should also be recognised^{26, 33}. The individuals who use these services have a range of diagnoses covering paediatric syndromes, neurological, orthopaedic, and musculoskeletal conditions, and learning disabilities.

Diagnoses

3.15 In published studies the commonest diagnoses amongst those who get special seating are:

Diagnoses	Medhat and Redford 1985 ³⁷	Lachman and Greenfield 1993 ³⁹	Ham 1993 ⁴⁰	Datta and Ariyaratnam 1996 ⁴¹
Cerebral Palsy	60%	40%	15%	85%
Muscular Dystrophy	30%	<10%		
Multiple Sclerosis		20%	25%	
Brain Injury		10%	15%	

Unmet need

- 3.16 These services were set up for long term disability and relatively stable needs and current response times do not allow for meeting the needs of three particular client groups.
 - 1. **Rapidly deteriorating conditions** such as Motor Neurone Disease or rapidly progressive Multiple Sclerosis in whom sitting tolerance and function can be optimised despite overall deterioration.
 - 2. Acute change e.g. clients such as those who have undergone major corrective surgery to their spines and/or hips.
 - 3. **Rapidly improving conditions** (most commonly single insult brain injury) on short term rehabilitation programmes who require specialised wheelchair seating to assist them in their progress²⁷.

Epidemiology

3.17 There are no national figures currently available from which the need for specialised wheelchair seating could be estimated. Bardsley et al (1984) conducted a comprehensive seating survey in Dundee and an average of 4.6 individuals per 1,000 persons in the total population surveyed (n = 204,000) had seating problems⁴². In a sample population of 3 million from North West London and Hertfordshire, there are a total of 55,000 wheelchair users (17 per 1,000 population) out of which 1,000 (0.34 per 1,000 population) require specialised wheelchair seating.

Approximate cost

- 3.18 Fife et al (1991) reported that in Vancouver, Canada, the cost of an individual seating system ranges from \$400 to \$5,000 (£250 to £3,500) and the mobility base such as the wheelchair cost ranges from \$1,000 to \$10,000 (£650 to £6,500) this includes powered bases³⁴.
- 3.19 The average cost of a specialised seating system in the UK is approximately £1,250 and a manual tilting base £600 (2003 prices). The cost of seating systems has not risen beyond inflation over the last 10 years³⁸ but recognition of the benefits of tilt in space has led to the development of tilting bases, which are now increasingly used, 53% in a recent audit at Stanmore⁴³.
- 3.20 Furthermore, the specialised seating and wheelchair base requires replacement every 3 to 5 years due to changing needs of the disabled person and wear and tear of the systems. These increased demands have generally not been matched by increased funding.

How are the specialised wheelchair seating services provided?

3.21 Specialised wheelchair seating services are usually provided under the umbrella of more generalised wheelchair and mobility services⁴⁴ but this model should not constrain development of services with more holistic approach to postural management.

Background

- 3.22 The following factors are essential to provide the specialised wheelchair seating services:
 - A philosophy of care that puts the disabled person at the centre of provision and care.
 - A holistic approach which brings together a range of professionals involved in the care of the disabled person including: medical, nursing, therapy, engineering, technical and social, from both hospital and community settings.
- 3.23 For efficient and cost-effective service provision collaborative commissioning is required⁴⁵ and the reasons are:
 - High cost low volume service.
 - Scarcity of staff with appropriate levels of specialist expertise.
 - A critical number of disabled people (a minimum of 500) accessing the service to develop and maintain the staff's specialist expertise.
 - Open channels of communication between the specialist and local wheelchair services.

4. Guidelines for specialised wheelchair seating

G1	Service commissioning and provision	Grade of Recommend- ation (see 2.17)
G1.1	Commissioners for services should ensure that collaborative commissioning arrangements are in place for a network of services, which include local wheelchair services supported by tertiary specialised wheelchair seating services.	$(\mathbf{C})^1$
G1.2	 Each geographical area should have a local wheelchair service and there should be clear guidelines for: Who should be referred to the specialised wheelchair seating service How to refer them 	(C) ^{1,6}
	Prioritisation of urgent cases to minimise waiting times especially those with rapidly changing seating needs.	
G1.3	Both commissioners and service providers should ensure that systems are in place for minimising waiting times especially for those with rapidly changing postural/seating needs.	(C) ¹
G2-6	The process of specialised wheelchair seating provision	

The process of specialised wheelchair seating provision includes the following steps and *risk assessment must be taken into account at all stages.*

- **G2** Referral and initial response
- **G3** Assessment and prescription
- **G4** Delivery
- **G5** Reviews and reassessments
- **G6** Maintenance and repairs

G2 Referral and initial response

A referral may be made by any professional agency, including medical, nursing, therapy and social services, or an existing service user, using locally agreed procedures.

- **G2.1** On receipt, the referral should be screened⁴⁶ and triaged within 48 hours by a $(C)^{1,6}$ member of the clinical team to determine:
 - The degree of urgency (urgent, semi-urgent or routine: see Appendix 1)
 - The relevant parties to be invited to the assessment.
- **G2.2** The referral should be acknowledged in writing, ideally by sending out an $(C)^{1,6}$ appointment, within five working days.
- **G2.3** If an appointment date is not immediately available the disabled person and/or the $(C)^1$ referrer should be:
 - Informed of the likely arrangements⁶
 - Given a contact name and number for future reference.

G2.4 The disabled person and the carers should be provided with information on:

- How to get to the assessment
- What to bring with them
- The assessment process
- How long the assessment might last

See Appendix 2 for an example of an information sheet

G3 Assessment and prescription

Assessment is normally undertaken in a specialist centre, with appropriate equipment, and suitable facilities for moving and handling. Alternatively, people may be seen in their own homes, or domiciliary locations (e.g. schools/Child Development Centres/Paediatric Centres for children, familiar surroundings for people with cognitive or learning difficulties), if more appropriate^{38, 44, 47}, or if environmental factors are paramount.

 $(\mathbf{C})^1$

The team approach to specialised wheelchair seating is well documented^{29, 47-51} and requires professionals experienced in the management of people with profound disabilities and their seating/postural needs.

The relative ratios of the members of the multidisciplinary team will depend on the configuration of the particular service. However, experience would suggest that for a service with 500 clients the minimum staffing ratios should be:

- 1.0 Whole Time Equivalent (WTE) Engineer
- 1.0 WTE Engineering Technician
- 1.0 WTE Therapist
- 0.5 WTE Doctor
- 2.0 WTE Administrative staff.

A standard proforma for assessment⁴⁶ may assist consistent gathering of information. A suggested template is given in Appendix 3.

G3.1 Assessment

Assessment should:

a.	Be carried out within a maximum of 13 weeks from receipt of referral or variance documented	$(\mathbf{C})^1$
b.	Be carried out by a multidisciplinary team (doctor, therapist and engineer) with the appropriate specialist knowledge.	$(C)^{1, 4}$
c.	Take into account the views and the wishes of the disabled people, their families, carers and treating therapists ^{19, 28, 31} . Written input from family, carers and therapists should be sought if they are unable to attend the assessment.	(C) ¹
d.	Be held in a location with appropriate assessment equipment and facilities for moving and handling (to minimise risk for the disabled person and the professional staff), which is usually a specialist centre.	$(B)^{52} (C)^{46, 52, 53} $
e.	 Include history taking and physical examination Undertaken by a clinician (doctor/therapist) with appropriate level of knowledge The main objectives of the examination are to define and determine: Posture (including fixed and correctable elements) Effects of gravity on posture 	(C) ¹⁹
	- Level of functional ability	

- Presence/extent of secondary complications such as shortening of muscles, contractures^{18, 19, 31}.

f. Be carried out with the knowledge of other postural management strategies, either current or planned (e.g. other postural equipment, medical or surgical interventions) that may affect the final outcome.	$(C)^{1, 50}$
g. Be aware of other integrated equipment in use to ensure continued use.	(C) ¹
The assessment process	-
The assessment process should:	(C) ¹
a. Be centred on the requirements and aspirations of the disabled person ^{20, 28, 31, 47, 53-55} .	
b. Ensure that the dignity of the disabled person is preserved.	
c. Be clearly explained to the disabled person and carers (both formal and informal). Allow sufficient time for language, communication and learning difficulties.	
Goal setting: establishing the objectives of the prescription	-
 a. The main goals and objectives of the prescription should address the aims of: The disabled people, their family and carers^{31, 56, 51} The professional staff involved in the disabled person's care¹ 	(C)
 The specialist wheelchair seating team¹. b. Goal setting should involve the individuals, carers and their families and differences of opinion should be resolved and agreed prior to prescription. 	(C) ^{57, 58}
 The goals/objectives should be "SMART" (Specific, Measurable, Attainable, Relevant, Time-related). 	(C) ⁵⁹
 d. The objectives should inform the outcome of the assessment which could be: A prescription for provision of a specialised wheelchair seating system³¹ (in most instances) <i>or</i> Alternative therapeutic, orthotic/surgical intervention followed by reassessment³¹ <i>or</i> Combinations of the above^{57, 5} <i>or</i> No specialised wheelchair seating system provision¹. 	(C)
Formulating the prescription	-
 a. Each prescription should be: Individually formulated to suit the disabled person's needs and lifestyle^{33, 60} Specified from the patient centred goals^{31, 56}. 	(C)
 b. If the most appropriate solution cannot be provided, the reasons should be fully documented e.g. environmental issues, pressure on resources, acceptability of the recommendations, etc. 	$(\mathbf{C})^1$
c. Consideration of alternative prescriptions should be made in relation to the factors listed in Checklist 1 and suggested in Checklist 2.	$(\mathbf{C})^1$
d. Where possible the proposed equipment should be trialled or simulated at the initial assessment or subsequent visits.	$(C)^{18, 19}$ $(C)^{28, 46}$
	$(\mathbf{a})^{\dagger}$
e. Each prescription should facilitate ongoing use of existing integrated equipment.	$(\mathbf{C})^1$

G3.5 Outcome

- **a.** At the end of the assessment a written report should be copied to the disabled $(C)^{1, 61}$ person and circulated with his/her consent to the relevant parties.
- **b.** The disabled person and the carers should be given
 - A provisional appointment for delivering the equipment *or*
 - A clear indication of the next stage(s) in their management plan.
- **c.** The disabled person and their representatives should be given contact details and (C)¹ informed of their responsibility for keeping the providing service advised of any relevant change.

G4 Delivery

Delivery is usually carried out at the specialist centre to access workshop facilities. *Risk assessment is particularly relevant at this stage of the process.*

G4.1 Delivery of equipment

Delivery should include:

- Satisfactory fitting of the specialised wheelchair seating system to the disabled person
- Incorporation of any other necessary equipment, e.g. communication aids, ventilator, etc.
- Formal testing of the whole system for suitability and stability
- Preliminary evaluation of achievement of objectives
- Education for the disabled person and carers on how to use the system^{57, 6}
- Formalised risk assessment (Appendix 4) 6 .

G4.2 Administration and process of delivery

- **a.** The completed seating system should be delivered within 13 weeks from (C)¹ assessment or reasons for variance recorded.
- b. Where a prescription is complex (e.g. seat shell from company A, headrest from (B)⁵² company B, and straps from company C) a named person with appropriate technical knowledge should track and co-ordinate assembly prior to delivery.
- c. The specialised wheelchair seating system should be delivered by one or more member(s) of the original assessment team. If this is not possible, a suitable staff member who has familiarised themselves with the original objectives should carry out the delivery.

G4.3 Education and provision of information to the disabled person and carers

The disabled person and the carers should be:

a.	Shown how to use and handle the system correctly including:	$(\mathbf{C})^1$
	Optimum positioningRecommended duration of use	
b.	Provided with:	$(C)^{6}$
	 A users' manual/written instructions on how to use the system with illustrations where appropriate^{26, 46} A copy of conditions of loan including their responsibilities regarding safe use, cleanliness and misuse of the system⁴⁶ 	

• Guidance on best practice for safe transportation of the specialised

 $(\mathbf{C})^1$

(C)

 $(\mathbf{C})^1$

 $(\mathbf{C})^1$

wheelchair seating system⁴⁶

- Contact details for problems and repairs^{46, 50}
- The written policy for reviews and reassessments^{1, 50}.

G5 Reviews and reassessments

Wheelchair services including specialised seating services should introduce systematic reassessment programmes for all users instead of relying on users to present themselves to their General Practitioner or tolerate equipment that they find hard to use⁴. This approach is likely to meet users' needs at an earlier stage, support user independence and prevent more expensive care at a later stage⁴⁷.

G5.1 Reviews

- **a.** Review should involve a check on:
 - Review of the disabled person's needs¹
 - Use, fit and appropriateness of the specialised wheelchair seating system^{29, 50}
 - Ongoing education about use of equipment¹.
- **b.** There should be a written policy:
 - Outlining the mechanisms for regular reviews
 - How a review can be initiated.
- c. Different types of review include:
 - Technical: By the engineer only to check the integrity of the system
 - Clinical: Joint review by a clinician and an engineer to check the system as well as the disabled person using the system
 - Multidisciplinary: The full team to re-evaluate the person and the appropriateness of equipment.

G5.2 Time frame for different types of reviews and reassessments

- **a.** First follow up review (3 months, by telephone possibly) after delivery should (C)¹ include:
 - Establishing to what extent the objectives (functional and postural) have been met
 - Assessing and recording the reasons for variance
 - Recording actions taken if the objectives are not met.
- **b.** Subsequent technical reviews (as advised by the manufacturer) should:
 - Check the safety and integrity of equipment
 - Assess the need for a clinical review.
- c. Clinical reviews, ideally every 6 to 12 months (See Checklist 3) should:
 - Reassess postural and functional objectives
 - Document change:
 - Growth
 - Posture
 - Medical condition
 - Ability and function
 - Life-style
 - Provide ongoing education on appropriate use of the system
 - Initiate appropriate action.

- **d.** Formal multidisciplinary team reassessment (ideally every 2 to 3 years) should be (C)¹ undertaken:
 - When the disabled person is outgrowing the system
 - Following major changes in life-style or medical condition (including surgery)
 - If there:
 - Is major dissatisfaction on the part of the disabled person and the carers
 - Is significant failure to achieve objectives
 - Are serious technical or safety concerns.

These time scales do not preclude 'ad hoc' referral due to unexpected change (medical or technical) or growth.

NB. The disabled person and carers must be made aware of their responsibility to inform the specialist wheelchair seating service of any changes which might have an impact on the specialised wheelchair and seating systems.

G6 Maintenance and repairs

G6.1	There should be a defined mechanism for maintaining and repairing the specialised wheelchair seating system in addition to the regular reviews.	$(B)^{62}$
G6.2	The disabled person and the carers should be made aware of how to access this service, as well as any constraints about the availability of maintenance and repair service.	(C) ¹
G6.3	Repairs should be prioritised on the grounds of risk assessment by the engineering staff.	$(\mathbf{C})^1$
G6.4	 There should be defined target for repairs such as: High risk (preventing safe use of the system): within 24 hours^{46, 6} Medium risk: within 3 days Low risk: within a month. 	$(\mathbf{C})^1$
G6.5	Any third party involved in repairs, must be aware of their responsibilities to notify dangerous equipment, both to the disabled person and the specialist seating team, and there should be an agreed mechanism to facilitate this.	(C) ¹
G6.6	The disabled person and the carers should be advised of their responsibility to keep the service informed of any relevant changes to their personal circumstances.	$(\mathbf{C})^1$

This document has intentionally omitted discussion of general funding issues. These guidelines have been commissioned to provide a steer to best practice and it is for commissioners of services to negotiate the resources to support best practice.

Useful checklists

Checklist 1:

Technical factors to be taken into account in prescribing a specialised wheelchair seating system and discussed with the disabled person & the carers

- \Box Durability⁶²
- □ Weight and size of the specialised seating and wheelchair system including the removable components⁶²
- □ Ease of removal of the seating system from the wheelchair base
- □ Load carrying capacity of the wheelchair base
- \Box Size of the specialised wheelchair seating system (assembled and dismantled)⁶²
- □ Manufacturing techniques and procedures
- **D** Regulatory requirements such as CE marking
- \Box Aesthetics (e.g. colour and appearance within the available range)^{62, 50}
- □ Transportability^{62, 50}
- □ Stability versus manoeuvreability
- □ Ease of cleaning
- Ease of adjustment for growth and change
- □ Ease of getting the disabled person in and out of the seating system in emergencies
- \Box (Cost) if applicable⁶²

Checklist 2:

Suggested check list when prescribing a specialised wheelchair seating system (Modified from³⁰)

- □ Is it needed? (*Is there an alternative?*)
- \Box Is it wanted? (*Will it be used*?)⁵⁰
- □ Is it acceptable to the disabled person?
- □ What are the trade-offs if any?
- □ What are the clinical implications if it is not used?
- □ Are there transportation issues?

Checklist 3: Suggested check list at clinical reviews/reassessments (Modified from³⁰)

- □ Has the provision achieved the agreed objectives?
- \Box Is it comfortable?⁶²
- Do the disabled person and his or her carers know how to use it?
- □ Can the carers manage it and use it appropriately on a day to day basis?⁶² (*e.g. for comfort, protection of vulnerable pressure areas*)
- \Box How does it fit in with the disabled person's lifestyle and his or her surroundings?^{62, 50}

Guidelines for specialised wheelchair seating

5. Areas for future research

5.1 As mentioned earlier in these guidelines, one of the problems has been the absence of sound data on which to base statements and draw conclusions. One of the difficulties for rehabilitation services in general and specialised wheelchair seating in particular is the dearth of academic foci to stimulate research in the field. Nevertheless it would be amiss if we do not take the opportunity to highlight a few areas for future work but this is clearly not a comprehensive list.

Mapping current Specialised Seating Services

5.2 Current services have grown up 'ad hoc' in response to clinical need. These vary greatly in size, staffing, location and equipment provision. It would therefore be helpful to formally identify these services (in order to define what is being provided, and where) and further work on this is needed⁶³. Information on geographical location might facilitate some rationalisation of services and comparative data on those who are being seen should assist quantification of the 'service gaps'.

Rapidly changing conditions

5.3 Wheelchair and seating services were not designed to respond to rapidly changing conditions, and specifically do not cater for short term needs e.g. post surgery. However there is no logic in spending money on short-term rehabilitation programmes/correcting deformities, if the equipment necessary to maintain the gains is not readily made available. Work is required on the scale of the problem as well as ways of developing mechanisms for responding to these needs in a timely manner.

Efficacy of seating

5.4 This is a large field, but in particular there is a need for evidence that seating is comfortable.

Seating and surgical intervention

5.5 Whilst there is some evidence that good postural management reduces the risk of subluxation of hip in children with cerebral palsy, there is less evidence to suggest protection from either development or progression of spinal deformities. However, there may be a relationship between good postural management and deferred timing of spinal surgery and all these issues will need to be addressed systematically.

Outcome measurement

5.6 There is a need for further work on determining satisfactory outcome, critically from a consumer, but also a service perspective. Careful documentation of goals and objectives is a start, but further work is needed on outcome measures, which are sensitive to change following seating interventions.

Areas for future research

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Appendix 1 A guide to categorising the specialised wheelchair seating referrals

Refer to Guideline 2.1

Categorisation of referrals is difficult without fully assessing the disabled person and therefore may be somewhat arbitrary. Nevertheless, to ensure equity of service, it is important to prioritise the referrals. If certain issues are unclear, it is best to discuss these further with the disabled person, the carers and the professional staff involved in their care for clarification.

1. Urgent:

- Recent surgery, which has altered the long-term sitting ability or posture*
- Pressure sores which are affecting the disabled person's ability to use the specialised wheelchair seating system
- The disabled person with a rapidly progressive or a deteriorating condition
- Major concerns for safety in the present system

2. Semi-urgent:

- Children (because of growth)
- Anticipated weight gain e.g. following a recent feeding gastrostomy

3. Routine:

• Adults with static conditions

* Short term needs after surgery should be resolved by discussion between the surgeons and the local wheelchair services, preferably in a planned process agreed prior to surgery

Appendix 1 A guide to categorising the specialised wheelchair seating referrals

Appendix 2 Client pre-appointment information sheet

Refer to Guideline 2.4

What to expect from your appointment

Your appointment may take some time to complete. It is advisable to come prepared, as it is possible that you will be at the centre for several hours.

If you are coming for a full clinic assessment, the appointment will take approximately 2 hours to complete. You will be asked how you are managing with you current system, your general health, and you will have a physical examination.

Please be aware that you will not go away with a new chair from that initial appointment.

When you come to your clinic appointment please remember to bring:

- your current wheelchair(s), including accessories such as trays and knee blocks etc.
- any orthoses you use currently (e.g. foot splints, spinal brace).
- your glasses if you need them for driving (EPIOC).
- suitable outdoor clothing if you are coming for an EPIOC driving assessment.
- information about any current medication you take and any surgery you have had or are waiting to have.
- if you use a hoist sling for transfers please bring it with you.
- please inform your current physiotherapist or occupational therapist of the appointment so they can attend if possible.
- It is a good idea to bring something to eat and drink, but please be aware that we do not have drink thickener or special cups on site.
- You will also need to bring any personal care items needed if you have to use the toilet (e.g. pads, urine bottle).
- For children anything your child may need, e.g. a favourite toy.

Facilities available on site:

- Free parking
- Wheelchair accessible toilet with a changing bench
- Hot drinks machine (30p) and water cooler (free)
- "Oxford" style hoist
- Snacks are available from the Patient's Centre, Broccles Restaurant elsewhere on site, or a snacks machine located in the foyer in the Orthotics Department.

We are here to answer any queries and you can call us on 000-000-00000. The office is open Monday to Friday from 9am to 5pm. There is an answer machine to take messages at other times. Appendix 2 Client pre-appointment information sheet

Appendix 3 Suggested template for a specialised wheelchair seating assessment proforma

Refer to Guideline 3

4.____

Name:	Reference No.:
Age:	Date of birth:
Home address:	Address of school/day centre (if applicable):

Primary referrer		
Name:	Address:	
List of clinicians and agencies currently involved in the disabled person's care:		
1.		
2.		
3.		

Assess	smen	t/Re-assessment	Doctor:
Date:	1	1	Therapist:
			Engineer:
Persons accompanying the disabled person and their role (family, carers, therapists, etc.):			

Diagnosis	Date of onset:	
Main deficits:	Physical/Communicative/Cognitive	
Physical deficits: Does diagnosis predi	Hemiparesis/Tetra/Para/Other Kyphosis/Scoliosis/Kyphoscoliosis/Other Subluxed/Dislocated hips/Other dispose to particular postural deformity?	

Reasons for referral

(Please include the disabled person and carers views where applicable)

Relevant medical and surgical history

Checklist

- Current (and planned) medication:
- □ Epilepsy and its control:
- History of behavioural issues:
- **□** Regular monitoring of spine and hips:
- □ Past and planned orthopaedic procedures:
- Other surgical procedures: (e.g. gastrostomy, intrathecal baclofen pump, etc.)

Lifestyle and aspirations

Checklist

- Environments in which the specialised wheelchair/seating system is/will be used:
- □ Methods of transportation including how the system is secured during transportation:
- **D** The disabled person and carers (formal and informal) views on aesthetics of the system:
- □ Information on education, employment and leisure:
- □ Care requirements:

Ability

Checklist

- U Vision:
- □ Hearing:
- Cognition/ Communication:
- □ Upper limb function:
- □ Feeding and swallowing:
- □ Bowel and bladder control:

Autonomy

<u>Checklist</u>

- Ability to control the wheelchair and seating system independently:
- □ Method of transfers:
- □ Ability to adjust seating position:
- Ability to minimise risks related to equipment use:

Well being including skin integrity

Checklist

- □ Pain, muscle spasms and heat intolerance:
- **D** Problems with sensation and ability to relieve pressure independently:
- Current pressure sores and their management:
- □ Previous pressure sores and their management:

Postural management

<u>Checklist</u>

- Current postural problems including sitting tolerance:
- □ Pattern of daily use of all postural management equipment including orthoses:

Additional equipment attached to/transported on the wheelchair

(e.g. Communication aid, ventilator, oxygen cylinder)

□ How attached and how operated

Examination In supine

<u>Checklist</u>

- Overall orientation of body segments, and ability to realign:
- **D** Presence of involuntary movements & primitive reflexes, how these can be inhibited:
- □ Analysis of any abnormal posture, fixed or correctable:
- **□** Range of movement of relevant joints and any restriction of movement:
- □ Muscle tone (note and quantify any abnormality):
- □ Sensation:
- Skin integrity including presence of pressure sores, surgical scars, etc:

Examination In sitting:

<u>Checklist</u>

- □ Level of sitting ability:
- □ Re-assessment of body orientation under the effects of gravity:
- Optimal axial rotation:

Note:

- 1. Photographs or videos should be taken to record posture and optimal orientation in space with appropriate consent ⁶⁴.
- 2. There should be use of validated scales in assessment such as Chailey level of sitting ability^{50, 64}, Oxford MRC scale for motor power, Modified Ashworth scale for assessing spasticity⁶⁵.

Agreed objectives from the seating assessment:

("SMART": Specific, Measurable, Attainable, Relevant, Time-related)

1.

- 2.
- 3.
- 4. 5.
- 6.

Decision from the seating assessment:

□ Provision of a specialised wheelchair seating system

- □ Alternative therapeutic/ orthotic/ surgical intervention
- □ Provision of a specialised wheelchair seating system after other interventions
- □ No specialised wheelchair seating system provision

Measurements:

- 1. Seat width:
- 2. Seat depth:
- 3. Seat to foot rest:
- 4. Axilla height:
- 5. Shoulder height:
- 6. Head height:
- 7. Knee width:*
- 8. Medial thigh length:*
- **if appropriate*

Proposed prescription:

Specialised wheelchair seating system:

Wheelchair base:

Appendix 3 Suggested template for a specialised wheelchair seating assessment proforma

Appendix 4 Suggested template for a risk assessment proforma

Refer to Guideline 4.1

Name:

Age (Date of birth):

Reference No.:

Current equipment:

Accessories:

Risk assessment

Checklist

- 1. Factors that could affect safety:
- **u** Transportation of occupant seated in specialised wheelchair seating system within a vehicle
- □ Altered centre of gravity of wheelchair due to fitting of seating insert
- □ Failure of user/carer to fit seating insert correctly to wheelchair base(s)
- □ Hoist transfers (higher risk of inappropriate positioning and increased risk of instability)
- Contact pressure

2. Identification of possible hazards

- a. Injury to the wheelchair user and/or other passengers in the vehicle (including the driver) **Risk: High/Low**
- b. Seating and wheelchair system has greater potential to tip forwards and/or sideways under normal operating conditions
 Risk: High/Low
- c. Detachment of seat from wheelchair(s) causing injury to user/ carer **Risk: High/Low**
- d. Poor or incorrect positioning in seat **Risk: High/Low**
- e. Risk of pressure sores **Risk: High/Low**
- f. Other hazards **Risk: High/Low**

3. Action to reduce identified risks

- a. Equipment prescribed may be restrained using appropriate means and advice given to the wheelchair user and carers aiming for best practice
 - Advice given regarding transportation of wheelchairs (Guidance on the Safe Transportation of Wheelchairs, DB2001(03), June 2001 available from Medical Devices Agency)
 - □ The Safety of Passengers in Wheelchairs on Buses VSE87/1 available from Department of Transport
- b. Static stability test performed at hand-over to judge overall stability and recommendations and advice given to wheelchair user and carers regarding use of the wheelchair and seating system
- c. Training provided at the hand-over to the wheelchair user and carers and handbook issued for wheelchair and seating
- d. Identify how carers will place client into seat and explore most appropriate solutions to any identified problems

Appendix 5 Expert Group membership and conflicts of interest

Expert group member	Representing
Linda Marks (Chair) Consultant in Rehabilitation Medicine Stanmore Disablement Services Centre North West London Hospitals Trust	Rehabilitation Medicine British Society of Rehabilitation Medicine
Patsy Aldersea Occupational Therapist Freelance consultant for Whizz-Kidz	Occupational Therapy
David Constantine Executive Officer <i>Motivation Charitable Trust</i>	Charitable sector and wheelchair user
Martin Ferguson-Pell Aspire Chair in Disability and Technology Director Aspire Centre for Disability Sciences Royal National Orthopaedic Hospital, Stanmore and Trustee for the Foundation for Assisstive Technology	Rehabilitation Engineering
Jan Gawronski Specialist Registrar in Rehabilitation Medicine, North London training rotation	Rehabilitation Medicine British Society of Rehabilitation Medicine
Joe Hennessy Member of Empower and Trustee of the Forum of Mobility Centres Motability, and The Disabled Drivers Association	Voluntary Sector and wheelchair user EmPOWER
Roy Nelham State Registered Clinical Scientist Retired Director of Rehabilitation Engineering Chailey Heritage Committee member and Immediate Past Chairman, Posture and Mobility Group	Rehabilitation engineering Posture and Mobility Group for England and Wales
Pauline Pope Consultant Physiotherapist (freelance) <i>Ex-Mary Malborough Centre,</i> <i>Nuffield Orthopaedic Centre,</i> <i>Oxford.</i>	Physiotherapy Chartered Society of Physiotherapy (CSP)

Conflicts of interest

All expert group and editorial board members signed a form to declare any potential conflicts of interest with the guidelines. These are summarised as follows:

- 1. All the expert members were still working for, or had recently retired from an organisation(s) whose work is related to the guidelines. Professional affiliations are therefore listed above.
- 2. One member had undertaken paid consultancy work for a children's charity that would have a direct interest in the guidelines.
- 3. One member runs a department that receives occasional funding for testing commercial products.
- 4. No individuals had any personal interest (such as personal shares) with any company that could be involved with the guidelines.

Appendix 6 Collaboration with other organisations

These guidelines have been developed by the British Society of Rehabilitation and are supported by the following national organisations:

Organisation	Address
British Society of Rehabilitation Medicine (BSRM)	C/o Royal College of Physicians 11 St Andrews Place, London NW1 4LE www.bsrm.co.uk
Chartered Society of Physiotherapy (CSP)	14 Bedford Row London WC1R 4ED www.csp.org.uk
College of Occupational Therapists (COT)	106-114 Borough High Street, London SE1 1LB www.cot.org.uk
EmPOWER	Rehabilitation Centre, Roehampton Lane London SW15 5PR www.empowernet.org
National Forum of Wheelchair User Groups (NFWUG)	c/o Peter Kemp 64 Buckingham Grove, Hillingdon UB10 0QZ
National Wheelchair Managers Forum (NWMF)	c/o Alex Winterstone, NWMF Secretary Manager – Independent Living Services East Chantry Clinic, Hawthorn Drive, Ipswich IP2 0QY www.wheelchairmanagers.nhs.uk
Posture and Mobility Group of England and Wales (PMG)	PMG Secretariat 29 Myrtle Close, Alphington Exeter, Devon EX2 8UX www.pmguk.co.uk
Whizz-Kidz	Elliott House, 10-12 Allington Road London SW1E 5EH www.whizz-kidz.org.uk

Other recent publications of the British Society of Rehabilitation Medicine include:

From Surgical Appliances to Orthotics: Towards an Effective Service' (1999) price: £7.00

'The effectiveness of rehabilitation: a critical review of the evidence' Supplement to Volume 13, Number 1 1999 of Clinical Rehabilitation Price: £6.00

> 'Electronic Assistive Technology' (2000) price: £9.50

Prescribing a Lower Limb Prosthesis (CD format) (2001) price: £10.00

Clinical Governance in Rehabilitation Medicine: the state of the art in 2002 Supplement 1 to Volume 16 of Clinical Rehabilitation (2002) price: £9.00

Amputee and Prosthetic Rehabilitation – Standards and Guidelines (2nd Edition) (2003) price: £12.00

> Vocational Rehabilitation – the way forward (2nd Edition) (2003) price: £20.00

Rehabilitation following acquired brain injury – National clinical guidelines Published jointly by BSRM and Royal College of Physicians (2003) price £16.00 from the Royal College of Physicians

Copies of these publications may be obtained by sending a cheque to

The British Society of Rehabilitation Medicine c/o The Royal College of Physicians 11 St Andrews Place Regents Park London NW1 4LE

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