

SPECIALISED SERVICES NATIONAL DEFINITIONS SET (2nd Edition)

The Assessment and Provision of Equipment for People with Complex Physical Disabilities (all ages) - Definition no. 5

Preface

36 specialised services are covered by the Specialised Services National Definitions Set (2nd edition).

The definitions were developed through national working groups (one for each service). Many clinicians, hospital managers, finance and information staff and commissioners were directly involved in working group meetings and many more provided comments during the consultation stages. Some of the definitions have been endorsed by the relevant national organisations.

The definitions identify the activity that should be regarded as specialised and therefore subject to collaborative commissioning arrangements. The definitions provide a helpful basis for service reviews and strategic planning and enable commissioners to establish a broad base-line position and make initial comparisons on activity and spend. It should be noted that, currently, many of the definitions have coding gaps and other information problems as well as a lack of agreed standard service currencies; further work is needed in these areas.

Production of the Specialised Services National Definitions Set is an iterative process. Over time new specialised services will be provided by the NHS whilst other services will become more commonplace and cease to be specialised.

Each definition is divided into two sections.

Section A provides descriptions of the various services covered. In most definitions, the existing pattern or model of service provision is described as well as the clinical service. Each definition includes a list of relevant national guidelines, such as DoH or Royal College of Publications, and identifies any national databases containing health outcomes information. Section A also includes sections on finance and information, examines the best way of identifying the relevant activity in information systems and acknowledges any coding gaps or difficulties. Most of the definitions include a recommended standard currency for the service (eg. banded bed days).

Section B includes specific issues considered to be important by the working group concerned. The views expressed in Section B are those of the particular working group and do not necessarily represent opinion within the DoH or the NHS. Resolving these issues is not within the remit of the definitions project.

It should be noted that the definitions are not service specifications nor do they prescribe service models or set service standards. Where national standards for a service already exist these may be referred to in the definition but specific decisions regarding the planning and procurement of a

specialised service are matters for NHS commissioners themselves to address. Inclusion of a treatment or intervention in a definition should not be taken to mean that there is established evidence of clinical or cost effectiveness.

Comments and suggested improvements to the definitions are very welcome and can be sent to the email address: specialised.services.defins@doh.gsi.gov.uk

Section A

1. General Description

This definition has been subdivided into five main areas:

- Prosthetics and complex orthotics (section 4.1)
- Specialised wheelchair provision including complex postural seating/postural management systems and specialised powered wheelchair controls (section 4.2)
- Communication aids (excluding all forms of hearing aids and cochlear implants Section 4.3)
- Environmental controls and other electronic assistive technology (section 4.4)
- Specialised aspects of telecare (section 4.5)

For all of these services, it is the expertise of the patient assessment process that determines the specialised nature of the service. Ideally it would be possible to describe the specialised elements of the service by the level of complexity of the assessment process. However, currently there are no standard tools available to do this and therefore at this stage these services are identified by the nature of the equipment prescribed rather than by the assessment process.

Whilst the focus of the definition is on specialised equipment, it is essential that commissioners look at the whole model of equipment service provision. A hub and spoke model may be an effective service delivery model for these services with the hub playing a key co-ordinating role whilst ensuring high standards are maintained throughout the service. The critical mass of patients dealt with by the hub ensures the multi-professional team has the range and level of skills to deal with specialist cases. The spokes provide services to a wider group of patients while ensuring appropriate referral back to the hub for

those patients requiring the full services of the multi-professional team. . The development of services should be informed by relevant user involvement.

The services included in this definition involve the provision of equipment to adults and children and are characterised by:

- the complexity of service user needs (complex physical/cognitive/language/sensory disability)
- the complex and expert nature of the assessment
- the need for effective training and on-going maintenance and user support
- issues of maximising procurement economies of scale

Whilst the services are based on the provision of equipment in some form, the hardware does not comprise the totality of any of these services. Specialist assessment, provision of equipment and training should be delivered as part of a total package of care, to ensure that service users are provided with the most appropriate equipment and are enabled to use it to optimal advantage.

The other aspect common to many of these services is the long-term nature of the provision. Users will often need provision throughout their lifetime. Commissioning arrangements should therefore provide the resources to review and maintain equipment in order to accommodate the changing needs of this client group.

There is a growing need for integrated links between these services. Developments in electronic technology make it possible for some users with complex needs to have communication aid, environmental control and wheelchair control functions provided by a single system. There are also those who do not require such sophistication, but who can be expected to benefit from telecare or 'smart house' technology. Some assessments for environmental controls are likely to result in the provision of a telecare solution.

2. Rationale for the Service being on the Specialised Services Definitions Set

These services are regarded as specialised for one or more of the following reasons:

- patterns of activity are very difficult to predict across one health district authority or even several primary care trusts acting together
- the provision of equipment is low volume, relatively high cost and often modified to meet an individual need
- specialist expertise is required to make effective assessment and advise on appropriate provision
- economies of scale can be achieved by providing this expertise and access to assessment stock and workshop facilities via specialist centres
- there is a need for high levels of technical and professional support over the long term
- a small, but significant number of severely disabled people need an integrated approach to their postural and mobility needs with various electronic equipment (such as environmental controls and communication aids, wheelchair control, computer use and robotics), if they are to attain and retain a degree of independence

3. Links to Other Services in the Specialised Services Definitions Set

Specialised equipment to improve mobility and communications may be required by some patients with spinal injuries, where this is required, this activity would fall within this definition. These patients may relate to one of the following definitions:

No.6, Specialised Spinal Services (all ages)

No.7, Specialised Rehabilitation Services for Brain Injury and Complex Disability (adult) – Complex rehabilitation/management of chronic disability - Some service users with severe injury will require management by specialised rehabilitation services.

No.8, Specialised Neurosciences Services (adult) - Neurosurgery

No.23, Specialised Services for Children – Complex rehabilitation/management of chronic disability. Some service users with severe injury will require management by specialised rehabilitation services.

No.25, Specialised Pathology Services (all ages)

No.32, Specialised Ear Surgery (all ages)

4. Description of Services, Currencies and Issues

4.1 Prosthetics and Complex Orthotics

Prosthetics (artificial limbs)

All aspects of care provided to people with a congenital limb deficiency or who have had amputation of a limb (or limbs) with the exclusion of the surgical episode, should be regarded as specialised services. Close links between the surgical team and specialist rehabilitation team should be established pre-operatively to ensure the best outcome. Contact with the service is typically lifelong. The specialist prosthetic centres in the UK are listed in Appendix 1.

The service offers specialist assessment and review; prescription, provision and maintenance of prosthetic limbs and specialist gait re-education and prescription of silicone cosmesis. The multi-professional team includes a senior prosthetist and other prosthetists

supported by a consultant in rehabilitation medicine (with a special interest in prosthetics), specialist therapists, counsellors and engineering personnel.

Complex orthotics

This service comprises the provision of an externally applied device used to modify the structural or functional characteristics of the neuro-muscular and skeletal systems.

Only some aspects of an orthotics service are regarded as truly specialised, this being determined by the complexity of the patient's condition. However the definition is being drawn more broadly at this stage because it is difficult both to separate complex from non complex activity and to identify the cost of individual orthotics which are often part of a package of care cost within other specialties. If it were possible to separate the activity, the commissioning of "off the shelf", less complex orthoses would not be regarded as a completely specialised activity, and the funding would be arranged at a more local level.

The fundamental key to the service is the provision of a complex, multi-disciplinary assessment to facilitate the correct prescription. The team will include consultants in rehabilitation medicine, consultants from the referring specialty, senior orthotists and other orthotists, specialist therapists, counsellors, rehabilitation engineers plus a clinical measurement facility. Orthoses provided may be "made to measure" or "off the shelf".

The service includes the following aspects:

- assessment
- prescription
- procurement/manufacture and delivery
- demonstration (and trial of equipment in some cases)
- training in the use of
- maintenance and repair
- review

Cases that will require access to specialised services include: high cost/low volume upper and lower limb orthoses, complex spinal bracing, cases requiring access to developing techniques, and any complexity of orthosis where a clinical risk is being taken and careful monitoring is needed.

4.1.1 Currencies

Prosthetics

Further work is required to develop appropriate currencies. Until these have been developed it is proposed that the total cost of the prosthetic service at the centres listed in Appendix 1 is identified.

Potential approaches to a set of currencies might include:

- cost per patient seen each year + cost of hardware
- an episode of care approach determined by level of amputation and the number of interventions involved
- waiting time from referral to assessment
- waiting time from assessment to supply

Complex orthotics

Currently costs for complex orthotics are often hidden within packages of care attributed to referring specialties. Until methods of distinguishing between complex and less complex orthotics are established, it is proposed that the cost of the orthotics service is identified. Appropriate currencies will be developed at a later stage.

4.1.2 Issues to be noted

The Audit Commission report 'Fully Equipped' made a number of recommendations on how the service could be improved including :

- NHS Trusts should establish annual fee contracts for prosthetic repairs
- Commissioner service specifications for prosthetic services should include access to counselling services

'Fully Equipped' gives useful background as well as a full list of recommendations

4.2 Specialised Wheelchair Provision including Complex Postural Seating and Specialised Powered Wheelchair Controls

A specialised wheelchair service covers provision of wheelchairs to meet long-term mobility needs of individuals. Equipment is provided following specialist assessment either by wheelchair service staff in NHS trusts or other prescribers who have undergone specialist training from the local wheelchair service. This equipment is generally provided as part of an ongoing package of care including typically: periodic clinical reviews, as well as wheelchair maintenance and repair. A more specialised service is required by a small percentage of wheelchair users with the most profound disabilities, where the assessment process requires greater knowledge and expertise than is often available in local wheelchair services, such a service would address postural needs as well as mobility.

Specialised services are required by people who meet the following criteria:

- those people whose posture or mobility needs can only be met with a high level of individual design input. This would be beyond routinely prescribed bespoke seating such as moulded seat inserts and would require consideration of static seating and 24-hour postural management systems
- individuals at risk of developing pressure sores who may require detailed pressure mapping as part of an assessment and prescription process
- those people whose posture and mobility needs may not be complex in their own right but nevertheless significantly impinge on their overall level of functional ability
- individuals requiring full medical and physical assessment
- those people who have the ability to control a powered wheelchair but are unable to use standard joystick controls

4.2.1 Currencies

Further work is needed to identify the best set of currencies for this service. However, it is vitally important that any currencies identified take into account the outcome measures of the users as well as the hardware supplied.

4.2.2 Other Issues

NHS wheelchairs are provided by 151 discrete services, each with their own patterns of working and their own prescription criteria. This produces profound inconsistencies which need to be addressed. There is the need for specialised wheelchair services to be delivered in a variety of settings by an expert consultant clinical scientist/rehabilitation engineer and specialist therapists, supported by a consultant in rehabilitation medicine. This approach will enable a specialised provision to be delivered safely and effectively.

Non-powered wheelchairs

Clinical and safety considerations demand that modification to standard wheelchairs should be overseen by experienced technical personnel.

Customised electrically powered indoor chairs (EPICs)

Similar clinical and safety considerations apply, but additionally there may be need for non-standard control systems, or for the safe integration of the wheelchair controls with those operating environmental controls or communication aids, a process normally overseen by the specialist therapists.

Electrically powered indoor and outdoor wheelchairs (EPIOCs)

The criteria referring to EPICs (8.2.2) apply together with issues concerning the EPIOC users' ability to satisfactorily and safely manage the wheelchair in the outdoor environment. **(Drafting Note: What is 8.2.2?)**

Special seating and 24 hour postural management.

Whilst better seating and cushioning can enhance comfort, improve posture and reduce the development of pressure sores, there is increasing evidence to suggest that consideration must be given to the 24 hour postural management of those with complex disability if the improvements gained through correct seating are not to be undone. If this is to be effectively and economically achieved there must be multi-professional and technical expertise available.

4.3 Communication Aids

This service includes expert assessment, followed by demonstration, trial and provision of a range of electronic and non-electronic communication devices, (augmentative and alternative communication systems). A communication aids service should offer user training, equipment maintenance (often supplied by the manufacturers of the equipment) on-going support and periodic review.

Communication aids assist people who have difficulty with speech (and / or language) or written communication. The services are distinct from those for people with hearing impairment, which are more usually managed in collaboration with ENT services.

The equipment includes aids to writing and reading as well as speech. Computer based aids (as well as some commercially available dedicated communication aids) can form an integrating link between communication and environmental control and telecare.

The specialised nature of the service may be characterised by:

- personnel with in depth knowledge of the field of Alternative and Augmentative Communication (AAC) with access to a wide range of equipment and
- access to the technology and techniques related to the development of the patient's vocabulary, especially when there is a requirement for integration with other electronic assistive technology

There are eight communication aids centres within England and Wales for the assessment and evaluation trial of aids and, in some cases, provision of equipment.

Local arrangements for the provision of equipment vary considerably across the country. Historically some are the result of ad hoc purchasing by a provider or commissioning agency to meet an individual assessed need; elsewhere, a dedicated budget is available to a community or hospital based rehabilitation team. Provision for school children may be arranged through the local education authority. The recently announced Community Equipment Services initiative (HSC 2001/008 : LAC (2001)13) and the Department of Education and Employment (DfEE) guidance is intended to influence significantly the availability of equipment on a national basis. The specialist centres can advise on the co-ordination of packages of care across the agencies of Health, Education and Social Services.

[Drafting Note: should this now be DfES not DfEE?]

The specialist centres, involving speech and language therapists, have further responsibility for the co-ordination of research and development programmes. This will involve the development of care protocols to include evaluation of outcome.

4.3.1 Currencies

Further work is needed to develop appropriate currencies for communication aids but initially all the activity at the communication aids centres should be identified as specialised.

4.3.2 Other Issues

Clarity regarding the detailed implementation and implications of the Community Equipment Services initiative (HSC 2001/008 : LAC (2001)13) and the DfEE also guidance in relation to funding responsibility for the provision of communication aids is required.

The DfEE initiative press release defines assessment of children for communication aids as being under the management of the British Educational Communications and Technology Agency (BECTa) and that “Detailed arrangements including the geographical coverage of the project will be the subject of further discussion between DfEE, BECTa and other interested parties.” Such discussion will be important to establish the relationship both clinically and financially between BECTa and specialised health services in respect of the most effective assessment practices.

The rapid development in the technology of this type of equipment requires a flexible approach to purchasing, as and when required. Computer based systems incur costs associated with upgrading software and hardware.

Appropriate arrangements for follow-up and re-assessment are essential. Many systems become redundant because of the lack of a systematic review process.

Around the country there are currently very different models of service provision. For this reason there needs to be some flexibility in drawing the lines between locally commissioned and specialised services.

4.4. Environmental Controls and other Electronic Assistive Technology

Environmental control (EC) systems are highly specialised equipment enabling people with severe physical disabilities to control access to their home, to summon emergency help and to operate domestic appliances. The range of appliances includes standard equipment already in the home such as music centres, television, video-recorders, digital service decoders, computers and electronic books. Specially designed remote control appliances are provided for telephone operation, paging carers and the control of domestic lighting.

As well as providing safety and security, EC systems can enhance significantly the independence and autonomy of the user while also easing the burden of caring. Systems vary enormously in complexity and are individually prescribed for the specific user’s needs. A significant proportion of users are able and are motivated, through their EC system, to make use of modern information and communication technology services for activities such as electronic shopping and accessing information from the Internet.

EC users are amongst the most severely disabled members of the community and require a comprehensive support service. This includes assessment, provision, equipment maintenance and periodic on-going clinical review the service. The service needs to be particularly responsive to the changing needs of those with an unstable illness

The service should be overseen by consultants or therapists with specialist knowledge in this area. There is an advantage in developing in-house NHS electronic engineering teams to complement those of system manufacturers and suppliers, but such developments must be to the benefit of the service users and not be solely a cost saving measure.

4.4.1 Currencies

It is felt that the contract currency for this service should be based on the population of service users who have functioning equipment installed in their homes. For inclusion in this population total, the service provider could have to demonstrate:

- where the user has been referred, or has self-referred for assessment or re-assessment, that any equipment required has been installed in a functioning state within three months of receipt of the referral (excluding deferment at the user's request or otherwise beyond control of the provider). This is to meet the NHS National Plan requirements for equipment provision. **(Drafting Note: Is this right?)**
- that, during the previous twelve months, the user has been contacted, either directly through the NHS provider or indirectly through a sub-contractor, to ascertain the user's level of satisfaction with the system and that any necessary re-assessment/remedial work has been scheduled. This is to ensure that the service provider is providing effective on-going support.

It may be appropriate to develop a set of currencies based on banded annual fees, and the formalising of an index of complexity and vulnerability would be an essential element of this service.

4.4.2 Other Issues

There are a number of specialist centres throughout the country, which supply specialist devices for activities of daily living. These are one-off or customised devices designed to meet the needs of individuals when they cannot be met by existing off the shelf systems. These centres provide important support for basic community equipment services when these cannot meet the needs of severely disabled individuals. Further contact details are available from the Disabled Living Centres Council (DLCC) - www.dlcc.org.uk

Technological progress has been rapid in this area. The provision of environmental controls should be linked with communication aids and integrated with other electronic assistive equipment. Commissioning will need to focus on coordinated specialised provision of electronic assistive technology, integrating environmental control and other electronic assistive technologies.

An understanding of the relationship between currently provided environmental controls and the implementation of telecare needs to be developed at a clinical, technical, training / education and service commissioning level.

4.5 Specialised Aspects of Telecare

Currently different agencies have responsibility for provision. There is a need for the provision to be carefully co-ordinated in order to ensure a fair and equitable provision.

Developments in information and communication technologies now make it possible to provide electronic systems which can support elderly and vulnerable people, enabling them to live safely in the community. This is an emerging technology and the range of applications can be expected to grow as new technologies are tested and validated. It is expected that much of the equipment will be of low cost/high volume and capable of provision through community equipment services. Resources for the specialised aspect of telecare provision should be developed within existing electronic assistive technology services and overseen by a consultant clinical scientists/ rehabilitation engineers or specialist therapist with experience and knowledge in this area.

Systems can:

- detect falls or hypothermic conditions and automatically summon help
- switch on appropriate lighting if someone arises from bed during the night
- detect if someone wanders
- provide electronic prompts for people with memory loss

There will be a need to:

- teach people about the benefits of telecare and to offer training to nurses, therapists and other health/social services staff through a variety of teaching/visual methods
- assist in the development of local networks
- evaluate new technologies and develop clinical guidelines for their implementation
- participate in multi-professional assessment in complex and difficult cases
- manage the installation process for non-standard installations

4.5.1 Currency

Telecare is an emerging technology which needs to be linked with all the services within this definition. Prices are likely to be based on individual packages, due to the need to identify personal solutions after assessment by specialist therapists and technicians.

5. National Standards, Guidelines and Protocols

- ‘Fully Equipped’ published by the Audit Commission (March 2000) is the second report in a series of four focusing on promoting independence for older and disabled people. Orthotic, prosthetic, wheelchair and postural management services and community equipment services are included within this report. The report highlights the deficiencies in the current provision of equipment services by the NHS and social services departments and makes key recommendations to improve standards and provide a fairer service.
- Report of the working group on the provision of speech and language therapy services to children with special educational needs (England), published 21 November 2000 (DfEE document ref. 0319/2000)

- "Electronic Assistive Technology" British Society of Rehabilitation Medicine Report, 2000 (formally endorsed by IPEM)
- British Standard, BS 2574: Part 3:1990. Lower limb orthoses: method for the determination of mechanical properties of metal knee joints and side member assemblies
- British Standard, BS 2574: Part 1: 1991. Lower Limb Orthoses: guide to the design and manufacture of lower limb orthoses, excluding foot orthoses
- British Standard, BS 2574: Part 2: 1994. Lower Limb Orthoses: specification for hip, knee and ankle joints for lower limb orthoses
- British Society of Rehabilitation Medicine 1999. From Surgical Appliances to Orthotics - Towards an Effective Service
- Amputee Medical Society 1997. Congenital Limb Deficiency

Section B

Note: The views expressed in the following section are those of the working group and do not necessarily represent opinion within the Department of Health or the NHS.

6. Issues to be Noted Regarding this Service /Definition

6.1 Information systems: Lack of investment and an uncoordinated approach to developing information systems and technology to support these services has resulted in a variety of stand-alone data collation processes that have evolved in response to local requirements. These have limited capacity to produce useful aggregated management information and to integrate with other systems.

6.2 Assistive Technology will be delivered at a centralised (specialised) level and a local level. Consequently some type of coordination (root and branch / hub and spoke / network) involving the following will be needed:

- referral criteria
- procurement efficiency
- nomenclature and terminology consistency,
- maintenance effectiveness and efficiency
- clinical and service quality standards

6.3 The increasing involvement of clinical engineers and technologists in this area of service has highlighted the need for appropriate professional supervision structures.

6.4 There are few (and in some areas none) agreed standards and outcome measures to judge standards of service delivery in these areas. These issues are closely related to clinical governance and the controls assurance agenda.

6.5 The provision of these services is related to the development of community equipment services (HSC2001/008:LAC(2001)13) and intermediate care (HSC20001/1:LAC(2001)1) needs to be considered.

6.6 It is important that there is equity of provision for communication aids regardless of age or postcode. There is concern that this currently may not be the case.

Appendix 1: Specialist Prosthetic Centres in the UK

1. Aberdeen
2. Belfast
3. Birmingham
4. Brighton
5. Bristol
6. Cambridge
7. Cardiff
8. Carlisle
9. Charing Cross
10. Cleveland
11. Crystal Palace
12. Derby
13. Dorset
14. Dundee
15. Edinburgh
16. Exeter
17. Glasgow
18. Gillingham
19. Harold Wood
20. Hull
21. Inverness
22. Isle of Wight
23. Leeds
24. Leicester
25. Liverpool
26. Luton and Dunstable
27. Manchester
28. Newcastle
29. Northampton
30. Norwich
31. Nottingham
32. Oxford
33. Plymouth
34. Portsmouth
35. Preston
36. Roehampton
37. Sheffield
38. Stanmore
39. Stoke
40. Swansea
41. Wirral
42. Wolverhampton

43. Wrexham

Appendix 2: NHS Purchasing and Supply Agency Wheelchair Categories

A) Manual/Non-powered Wheelchairs (Categories)

1. Basic chair – user propelled
2. Basic chair – attendant pushed
3. Basic chair – modular
4. Heavy duty chair
5. Lightweight chair – user propelled
6. Lightweight chair – attendant pushed
7. Lightweight chair – modular
8. Compact chair
9. Active chair
10. Children's chair
11. Comfort chair
12. Tilt in space chair or chassis unit

B) Powered Wheelchairs (Categories)

1. Indoor powered chair
2. Heavy duty indoor powered chair
3. Indoor/outdoor powered chair
4. Heavyduty indoor/outdoor powered chair
5. Comfort powered chair
6. Tilt in space powered chair or powered chassis unit