SPECIALISED SERVICES NATIONAL DEFINITIONS SET (2nd Edition)

Complex Specialised Rehabilitation for Brain Injury and Complex Disability (adult) - Definition No. 7

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

A 'complex (specialised) rehabilitation service' may be broadly defined as:

"A service for patients with severe complex disabilities whose rehabilitation needs are beyond the scope of their local district rehabilitation services and is best commissioned collaboratively "

Complex specialised rehabilitation services which require collaborative commissioning are high-cost, low-volume services catering for injury or illness resulting in complex disabilities - (i.e. physical, communicative, cognitive and/or behavioural deficits.

Numerically, the most significant cause of such deficits is brain injury (due to any cause including trauma, severe cerebrovascular accident, infection/inflammation, post-surgery, hypoxia.

However, other causes of complex disabling conditions include:

- Multiple trauma
- Severe musculoskeletal or multi-organ disease (e.g. rheumatoid arthritis with neurological complications)
- Co-existing spinal and brain injury
- Physical illness/injury complicated by psychiatric or behavioural manifestations

Under certain circumstances, patients with neurological conditions such as multiple sclerosis or Guillain-Barre syndrome may have particularly complex rehabilitation needs that are better met by a complex specialised rehabilitation service.

For reasons explained later in this document, this definition covers all rehabilitation activity that is undertaken within those centres that each are identified by commissioners as providing a significant proportion of complex specialised rehabilitation as opposed to local level rehabilitation.
The terms 'specialised' and 'specialist' have led to considerable confusion. Any rehabilitation service provided by a multi-disciplinary team which includes a consultant specialist in rehabilitation medicine is a 'specialist rehabilitation service' according to the definition given by the British Society of Rehabilitation Medicine. The Royal College of Physicians Blue Report ("Physical Disability in 1986 and Beyond") makes the clear recommendation that every "district" (250,000 population) should have such a service. That document also recognised that, for certain uncommon complex conditions such as severe brain injury which requires highly specialised skills and facilities, it was both more practical and more cost-effective to provide services to a regional catchment (1-3 million population).*

Strategic planning of these regional services by individual primary care trusts (PCTs) is inappropriate and requires collaborative or ('specialised') commissioning by groups of commissioners. This document describes these low volume, high cost services for individuals with complex rehabilitation needs but puts them in the context of the full range of rehabilitation services. The document refers to these services as 'complex' specialised services. There is no established definition of 'low volume' but for these purposes it could be estimated at 10-20/100,000 population.

Note:* District is taken to mean an area often similar to that covered by a PCT, covering a population of 250,000. Region is taken to mean an area, often similar to a former Regional Health Authority (there were 16) or one or two Strategic Health Authorities covering a population of 1-3 million.

2. Rationale for the Service being included in the Specialised Services Definitions Set

Injury to independence – the changing face of rehabilitation

Fundamental to understanding rehabilitation is the awareness that different patients need different things. Moreover, the same patient needs different things at different stages in recovery:

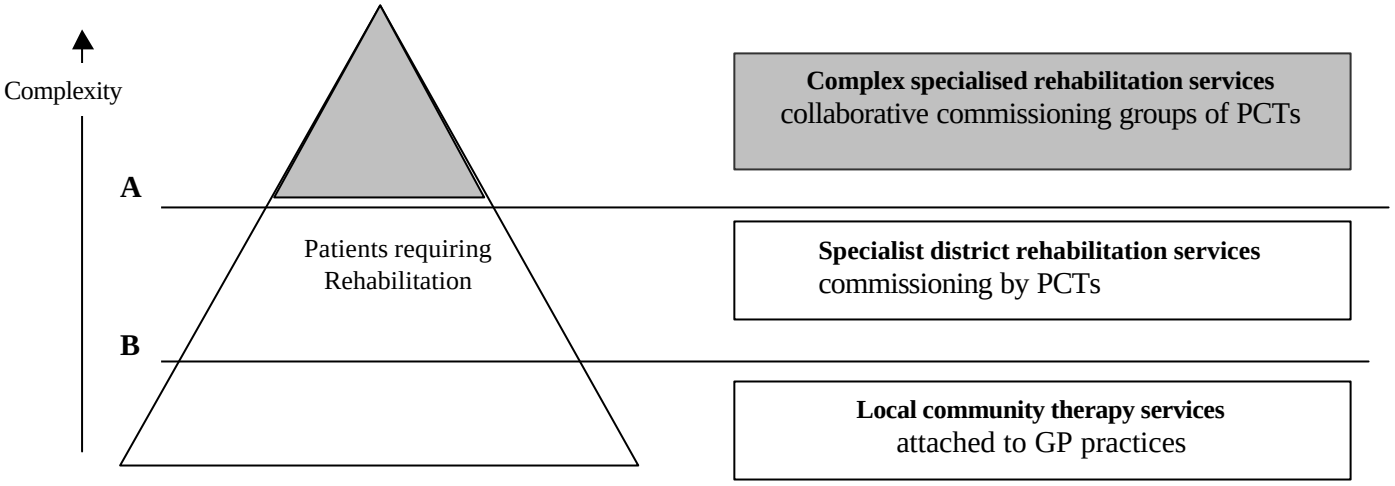
- **Acute care**: Following severe insult or injury, the patient often requires acute care in hospital for up to a few weeks. Rehabilitation should start as soon as possible and, in the acute stage, should focus on nursing care and therapy that reduces the consequences of immobility, confusion, bulbar dysfunction (swallowing and breathing difficulties) and learned behaviour
- **Post-acute in-patient rehabilitation**: Specialist rehabilitation comes into its own in the post-acute stage as the patient starts to recover and needs to make the transition between hospital and community. It focuses on regaining the skills of independent living to allow the patient to manage at home
- **Community rehabilitation**: Once back at home, patients need continued input to maximise their ability to function in their environment. Depending on the goals for that patient, this may require visits back to the hospital to use special facilities there (day or outpatient services) or may be more appropriately undertaken in the patients own familiar surroundings by an outreach team or domiciliary therapy
- **Continued support for disabled individuals and their families:** In the long term most patients will not require continuous rehabilitation, but may need drop in clinics or access to services or information by self-referral. Integration of health, social services, education and employment authorities is important to optimise function and minimise handicap

It is not a question, therefore, of providing services 'either in the hospital or the community'. Each area requires a network of inter-linked complementary services, with flexible funding arrangements to ensure that each patient has access to the most appropriate service for their needs at each stage in their recovery. This poses a considerable challenge for the new commissioning arrangements. Some possible models are described in more detail in Appendix 1.

Complex specialised rehabilitation services

The majority of patients with mild to moderate injuries will travel satisfactorily down the path from injury to independence with the help of their local (high volume) district services. A small minority, however, will have particularly severe or complex problems and require the services of a complex specialised rehabilitation service to progress (Figure 1).

Figure 1: The different levels of rehabilitation service provision (the top tier above A denotes specialised service)



Development of rehabilitation services to date

Development of rehabilitation services in the UK has been relatively slow and there are many different models. Some areas have developed services around regional and supra-regional centres, with quite well-defined local and complex specialised rehabilitation services. In other areas, there is no regional service and local district services have developed to a very high level – some of them also providing specialist rehabilitation to out-of-area patients. In yet others, there is no specialist rehabilitation service of any sort. The cut-off point for 'complex rehabilitation needs beyond the scope of their district services' therefore varies depending on the services available in the area, rather than the characteristics of the patient *per se*.

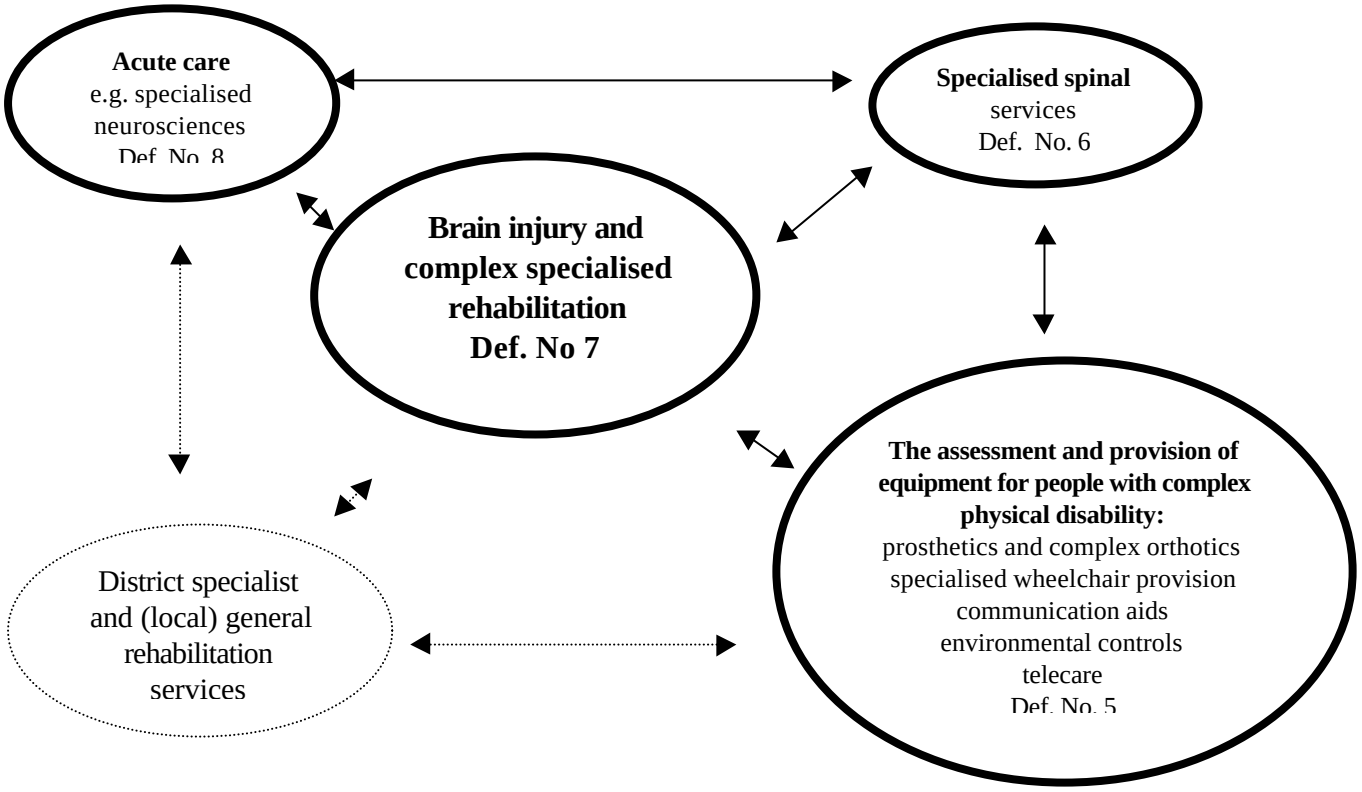
Because of the difficulty of separating local district and complex specialised services within a single unit, much debate has centred on whether the cut-off point for specialised service commissioning should occur at line A or B on Figure 1. It is not possible to be prescriptive, or to separate 'specialised' and 'non-specialised' activity within one service. Specialised services commissioning groups will need to work together with local providers, (including those in the independent sector) and with individual primary care trusts, to identify those services that currently provide mainly 'complex specialised rehabilitation' which are best commissioned collaboratively. This arrangement, however, places a great onus on primary care trusts and NHS Trusts and to recognise also the importance of supporting and developing the specialised rehabilitation services within their locality and in partnership with neighbouring commissioners.

There is a shortage of expert rehabilitation professionals in all disciplines and multi-disciplinary rehabilitation teams take years to develop. It is important to support and develop existing services to their maximum potential before starting up new ones

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

Figure 2 shows the links between this complex specialised rehabilitation service definition and other defined specialised services. It should be noted that many services provide activity which falls under more than one definition.

Figure 2: Relationship with other Services in the Specialised Services Definition Set



Brain injury rehabilitation will start during the acute phase of care in neurosciences units. Many patients following mild to moderate injury will make a swift recovery and be passed on to the specialist or general rehabilitation services in their locality. A minority of patients with severe injury will present with more complex rehabilitation needs and be referred to these complex specialised rehabilitation services. Such patients are likely to require equipment provision from the complex physical disability services as they progress towards long-term care in the community.

It is impossible for complex specialised rehabilitation services to function in isolation. Each should establish close links with a network of complementary local rehabilitation and supporting services (social, employment, education, etc.) for managing the life-long effects of brain injury.

No.30, Specialised Vascular Services (adult)

No.31, Specialised Pain Management Services (adult)

No.32, Specialised Ear Surgery (all ages)

No.34, Specialised Orthopaedic Services (adult)

4. Detailed Description of Specialised Activity

The definition refers to ‘patients with complex rehabilitation needs beyond the scope of their local district service’, but it is difficult to have a standard definition of ‘complex rehabilitation needs’ within this context. A number of characteristics are, however, identifiable as hallmarks of ‘complex specialised ‘rehabilitation services’ which provide for needs that often cannot be met sufficiently by local district rehabilitation services and these are set out below.

- **Inpatient services** – because of the requirement for intensive treatment and dependency level of patients, most complex specialised rehabilitation services are primarily inpatient services
- **Day and outreach services** – those services that provide follow up rehabilitation and support to patients with particularly complex needs
- **Co-ordinated inter-disciplinary management** – this is provided from a team of specialist therapists, nurses and doctors trained and accredited in rehabilitation. Co-ordination is achieved by integrated multi-disciplinary activities - e.g. case notes, ward rounds, case conferences, discharge planning, etc. Frequently it involves simultaneous input from more than one discipline in a single therapy session to address a specific task
- **Activity/rehabilitation trained nurses** – a critical factor in complex rehabilitation is the ability to use rehabilitation skills in daily activities on the ward. Rehabilitation is a specialised area of nursing which requires a different approach from the traditional nurses' role
- **Intensity** – intensive therapeutic input is required, usually for several hours a day. Patients with complex physical deficits may require two or even three physiotherapists at a time to handle them
- **Duration** – a course of rehabilitation may typically last for 2-6 months or longer depending on the goals for rehabilitation and the individual needs of the patient
- **Dependency / severity** – patients are likely to be highly dependent or severely injured (often both) with physical, communicative, cognitive and/or behavioural problems
- **Complex discharge arrangements** – many patients require continued support or are unable to return to their own homes and so require co-ordinated discharge planning involving health, social services and often employment / education authorities
- **Age** – most complex specialised rehabilitation services are targeted at adults who are young in body and mind, even if there is not defined age cut-off. Paediatric rehabilitation services are included within Specialised Services for Children – Definition No. 23
- **Equipment and facilities –** complex specialised rehabilitation services may offer a range of equipment and facilities not available in more general services and therefore may act as demonstration centres for assessment of suitability for prescription – e.g. of electro-assistive devices, special seating systems, specialist orthotics, etc.

Specific services offered as part of complex specialised rehabilitation services

In general, complex specialised rehabilitation services offer services that meet the standards of specialist inpatient rehabilitation services as laid down by the British Society of Rehabilitation Medicine (BSRM). In addition, they may offer some or all of the following specific inter-disciplinary procedures as part of their service:

- **Behavioural / cognitive / neuropsychology rehabilitation programmes** – either for "walking-wounded" brain injured patients or those with complex behavioural syndromes in association with physical disability
- **Coma-arousal programmes** – for patients in vegetative or minimally responsive states
- **Spasticity management** – multi-disciplinary programmes for spasticity management including intrathecal baclofen pumps, botulinum toxin in conjunction with serial splinting / orthotic management / postural management programmes
- **Tracheo-pharyngeal management** – tracheostomy weaning together with dysphagia assessment (video-fluoroscopy, etc.)

- **Electro-assistive technology / communication aids / computers in disability** – application of state-of-the-art technology for improved independence and quality of life
- **Back to work programmes** – vocational and social rehabilitation in the light of complex physical and sensory disabilities, work assessments, employer negotiations, financial counselling, etc.
- **Sexual counselling** – for disabled people and their partners
- **Inpatient complex rehabilitation assessment for physical and complex disabilities**
- **Group therapy programmes –** one advantage of a central unit is the opportunity to convene groups of patients with a common problem. Group sessions allow patients to gain not only from therapy but from the experience of engaging with others who have similar problems Group programmes may include: social interaction, extended activities of daily living, awareness of current affairs, high level communication skills, work skills, etc.
- **Cognitive behavioural therapy programmes** - for chronic pain syndromes, chronic fatigue, conversion or 'enhanced disability behaviour' states
- **Treatment of patients under sections of the Mental Health Act**
- **Formalised family support** to educate, advise, and facilitate family / carer function in the context of the patient's immediate and long-term dependency

In summary, while complex specialised rehabilitation may have many different facets, it may be possible to assess 'complex rehabilitation needs' in terms of:

- increased dependency on therapy or nursing in terms of staff time, number of people to handle, frequency or duration of input
- the requirement for specialist staff skills and training in certain physical, cognitive or psychosocial areas
- the requirement for special equipment or facilities, or for a peer group of patients with similar problems

Fixed cut-off points between complex specialised and local district specialist rehabilitation services are impossible to define at the current time, and must vary depending on the level of local service development.

5. Recommended Units of Currency / Approach to Costing

Because brain injury and complex specialised rehabilitation is a low volume, high cost activity, targeted closely on the needs of the individual, the majority of units currently monitor their contracts in cost per case or bed days rather than completed episodes. Day patient treatment or one off assessments are usually offered at cost per session.

In addition, some units offer limited numbers of fixed cost intervention programmes – e.g. a six-week pain programme at a standard cost. However, these are relatively unusual because handicap is strongly dependent on individual goals and aspirations, so programmes which are demonstrably effective in reducing handicap (increasing participation) are most commonly those orientated around individual patient goals.

While it would be beneficial to move towards a national standardised approach to banding based on complexity, there is not at present agreement with respect to what to measure or what tool to use to do this. Once the complex specialised rehabilitation services have been identified, bed days should be used

as the currency for this service but more work will need to be done before there is agreement about the number of bands that should be used.

Elements of service

The major cost element in most rehabilitation services is staffing. The Royal College of Physicians' Blue Report proposed minimum staffing levels for local district rehabilitation services of 1 nurse per bed, 1 occupational therapist for every 5 beds, 1 physiotherapist and 1 speech and language therapist for every 6 beds and 1 psychologist for every 15 beds. These are minimum levels that do not adequately allow for annual/study leave or sickness. Complex specialised rehabilitation services offering more intensive and more specialist therapy may be expected to require higher staffing levels, both in terms of numbers and grade.

Costs between units will vary considerably because each of these specialised services may have its own focus and sub-specialisation. For example, some post-acute services may have the facilities and backup to take on patients with active medical or surgical needs, tracheostomies etc., while others may not and so require that patients are medically stable as a criterion for admission. There are, however, broad cost bands and within the pricing for a particular service there will often be sub-banding reflecting heavy, medium or light categories of dependency.

"Dependency" in this context may reflect the needs for heavy nursing care or for more intensive specialist therapy input. Where such banding is applied, it is recommended that this be accomplished using validated instruments designed for the purpose. For example, the Barthel Index and the Functional Independence Measure (FIM) are validated measures of dependency in self care, and the Northwick Park Dependency Score has been developed specifically for assessment of nursing dependency in rehabilitation settings. A number of therapy dependency tools are currently in development.

In some instances, one off additional costs may be negotiated for individual patients, such as the cost of 'specialing" or one-to-one nursing for patients with severe aggression or behavioural problems. While this may seem a very high individual cost it is often necessary in order to ensure the safety of staff and other patients, which at the same time avoiding the need for restraint or sedation which would hinder the rehabilitation process.

Patients undergoing complex rehabilitation who require specialist equipment such as environmental control systems, special seating etc. may qualify for provision from the services which come under Definition No. 5 "The Assessment and Provision of Equipment for People with Complex Physical Disabilities". Some, however, fall outside the criteria for provision from those services, and may need to have their specific requirements met by individual negotiation with the relevant funding authorities.

6. Approach to Identifying Activity in Information Systems

Commissioners will need to identify the services in their area that provide a substantial quantity of complex specialised rehabilitation. Once these services are identified, all activity within these services should be considered specialised until there is a way of separating out any local less complex activity.

It is difficult to identify complex specialised rehabilitation services in terms of the characteristics of their patient load because patients with similar impairment, disability and handicap will be found in district, local services, depending on their stage of rehabilitation. Complex specialised rehabilitation services are

distinguished more easily in terms of their referral patterns and contracting arrangements, or type of rehabilitation input they provide.

Referral patterns and contracting arrangements

In areas where there are existing defined regional complex specialised rehabilitation services, identification is relatively easy. One approach would be to establish a designated list of brain injury and complex specialised rehabilitation centres, including services in the private sector which are currently purchased by commissioners. As a rule these complex centres will be identified by the following features:

- **Tertiary centres** accepting referrals primarily from another consultant (although some patients may be referred by GPs) usually from a wide catchment area
- **Current contracts with multiple Health Authorities** in some areas these services may already be commissioned collaboratively by Health Authority consortia. It should also be noted that many of these services cover populations greater than 3 million
- **Selection criteria** published selection criteria specify the type of patient who can benefit from the service and an **agreed referral protocol** is often in existence to identify suitable candidates. In each case this is locally defined, to take account of the availability of other local services. Patients not meeting the agreed criteria are referred on to other services more suited to their needs

Codes for in-patient activity

Complex specialised rehabilitation services do not lend themselves to the existing clinical coding systems used for hospital activity analysis since coding tends to focus on diagnosis rather than type of deficit or intervention offered. Some codes do relate to rehabilitation activity however, or describe the symptoms or "late effects' of certain causative conditions. Coding for rehabilitation will, however, need to become a great deal more sophisticated if it is to distinguish 'specialised' from 'specialist' rehabilitation activity. While there is potential for future development, it is unlikely that useful information can be derived retrospectively from coding in its current state.

7. National Standards, Guidelines and Protocols

The British Society of Rehabilitation Medicine (BSRM) has published clinical standards for in-patient specialist rehabilitation services (Clinical Rehabilitation 2000; 14: 468-480), and a similar set of standards for community and outpatient services is currently being developed.

Individual services differ somewhat, and not all of the standards are appropriate for every service. The standards are not minimal, but high level standards and can be categorised as follows:

- Standards which are pertinent and providers are expected to meet
- Standards which are relevant and providers would aspire to meet, but cannot do so at present
- Standards which are irrelevant to provider's particular service

Specialised local services would also meet many of the standards, but in general collaboratively commissioned services would be expected to show a higher level of compliance.

Accreditation of services

There is no formal accreditation system for rehabilitation services in the UK as yet, but the BSRM has piloted a scheme of multi-disciplinary peer review for services. In this scheme, the host service is visited by a multi-disciplinary review team which reviews the service in relation to the BSRM standards and

other issues brought up by the host service. Again the peer review system may be used for services at both complex and local specialist level.

Outcome measures for brain injury rehabilitation

The brain injured population is heterogeneous, both in terms of deficits and goals for rehabilitation. The major outcome for any rehabilitation programme is achievement of the individual's planned goals. Although various systems have been devised for goal attainment scoring, these do not provide comparative information between services. Currently a huge range of different measures is in use throughout the UK. Outcomes from rehabilitation programmes will depend substantially on severity of impairment and injury, so whichever measure is used must be recorded on admission as well as discharge to determine case mix. The major purpose of comparison is to be able to describe different programmes and plug gaps in service provision, rather than provide competitive comparison of units in terms of discharge outcomes.

To be able to compare different populations and programmes, however, some form of common language outcome measurement is required. This has caused much debate in rehabilitation, since no single outcome measure is suitable in all cases or settings. In an attempt to narrow the range somewhat, the BSRM has developed a 'basket' of recommended outcome measures for rehabilitation, selected on the basis that they are validated measures in routine use by at least 10 units. The list is available on the BSRM website (www.bsrm.co.uk).

A survey of specialist rehabilitation units in 1997 (Clinical Rehabilitation 1997; 11: 306-3) demonstrated that 95% of the units which routinely scored at least one standardised outcome measure used either the Barthel Index, the FIM or the FIM+FAM. All three of these are included in the BSRM basket.

The Barthel Index is a simple and reliable measure, which is widely used. Its main drawback is that it offers no direct assessment of cognitive and psychosocial function which are often the main factors to limit outcome in brain injury. There are also several different versions of the Barthel Index in current use, which confounds direct comparison. At the other end of the scale the FIM+FAM includes assessment of cognitive and psychosocial function, but is more complex and time-consuming to score. Currently individual rehabilitation units weigh up the relative merits of a simple instrument, or a more detailed but cumbersome one, and make their own choice.

As yet there is no formal national system for central collation of outcomes from brain injury rehabilitation, and there is no central system for data collection. A number of brain injury units contribute voluntarily to a centrally collated database recording the UK FIM+FAM through a collaboration which also ensures consistent training and use of the instrument. The UK FIM+FAM database also provides automated translation to a FIM score or a Barthel Index. There is potentially, therefore, a common language in outcome measurement at the level of the Barthel Index for the majority of specialised rehabilitation services in the UK. However it would be necessary to establish a greater degree of consistency in usage of the Barthel Index before this data could be submitted to any formal comparison.

Endorsement: The British Society for Rehabilitation Medicine

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.

8. Issues to be Noted Regarding this Service / Definition

While it is recognised that the current exercise involves identifying existing services that should be commissioned collaboratively, it was noted that the existing provision falls well short of current requirement, let alone future requirements, for brain injury and complex rehabilitation. A recent report of Brain Injury Rehabilitation from the Royal College of Physicians recommended that there should be 60-80 rehabilitation beds per million population to meet current needs. A survey undertaken as part of that report demonstrated a national average of around 30 with some as low as 20 per million.

Improved emergency care of acute brain injury inevitably leads to increased survival of profoundly brain-injured individuals. In future, additional investment in rehabilitation services will be required to maintain flow of acutely injured patients through the country's major acute hospitals servicing trauma and neurosurgical care, and back out into the community.
New technologies and equipment emerge from time to time which may impact on rehabilitation services. These may have significant up-front cost implications, even though they are ultimately shown to be cost-effective. Moreover, while the initial costs will typically be borne by healthcare, the main benefits accrue to social services in reduced long-term care costs. Joint commissioning between health and social services becomes increasingly important in order to gain maximum benefit from these emerging technologies.

Because of the relative sparsity of complex rehabilitation services, close integration of those services that do exist is necessary to leave as few gaps as possible. These specialised services have an important role to play not only in providing a high standard of clinical care but in acting as a focus for health services research and training for all disciplines involved in rehabilitation. Specialised services commissioning should include the continued allocation of funds for these activities to ensure an adequate supply of suitably trained staff as well as the evidence base to provide for the complex rehabilitation needs of the next generation.

This document attempts to define the 'complex' or 'tertiary' level of rehabilitation service, but these can only function efficiently if 'district' or 'secondary' local level services are available to meet the needs of the high volume conditions such as stroke. There is a need both for resources and training in rehabilitation at local level which must be provided not instead of, but as well as complex tertiary services. Co-ordinated inter-disciplinary rehabilitation is shown to be not only effective, but cost effective in reducing the need for long-term care. Suitable investment in this crucial area of healthcare is long overdue.

Appendix 1: Models for Provision of Brain Injury Rehabilitation

1.1 Definition of brain injury rehabilitation

There are many published definitions of rehabilitation most of which read along the following lines:

"Restoration of an individual to optimal physical, cognitive, psychological and social function following injury".

Broadly, rehabilitation offers three main approaches:

- Restoration of damaged function - for example, getting the patient up on their feet again
- Compensation for lost function, using a variety of equipment, aids and adaptations
- Helping the patient to take back control over their own lives, maximising activity and participation both on a functional and psychosocial level

Rehabilitation is not 'just for Christmas' – very often it means life-long support of those who have to live the rest of their lives with permanent disability. Not only are they prone to a variety of medical conditions, such as pressure sores, infections, contractures, etc., but in addition, they and their families need support to cope with the psychological, social and economic consequences of their disability. Management of chronic disability and acute rehabilitation require very different skills and services.

Following brain injury many patients will fortunately make a good recovery, but sadly not all. At the very severe end of the spectrum, patients may remain in 'persistent vegetative' or 'minimally responsive' states for the rest of their lives, requiring total care. Those less severely injured may make a partial recovery returning home, but requiring support to adjust to and live with their disability and handicap. A very much larger group suffer apparently minor injury (often not even requiring hospital admission), but subsequently have high-level cognitive deficits such as memory and/or attentional problems or altered personalities, which disrupt their lives and those about them.

Patients who have continued deficits following head injury thus fall into two main groups:

- Those with physical deficits – paralysis, contractures, etc., – as well as a range of cognitive and communicative problems
- Those who make a good physical recovery, but continue to have cognitive and/or behavioural problems with all the accompanying emotional and psychosocial consequences – the so-called 'walking wounded'

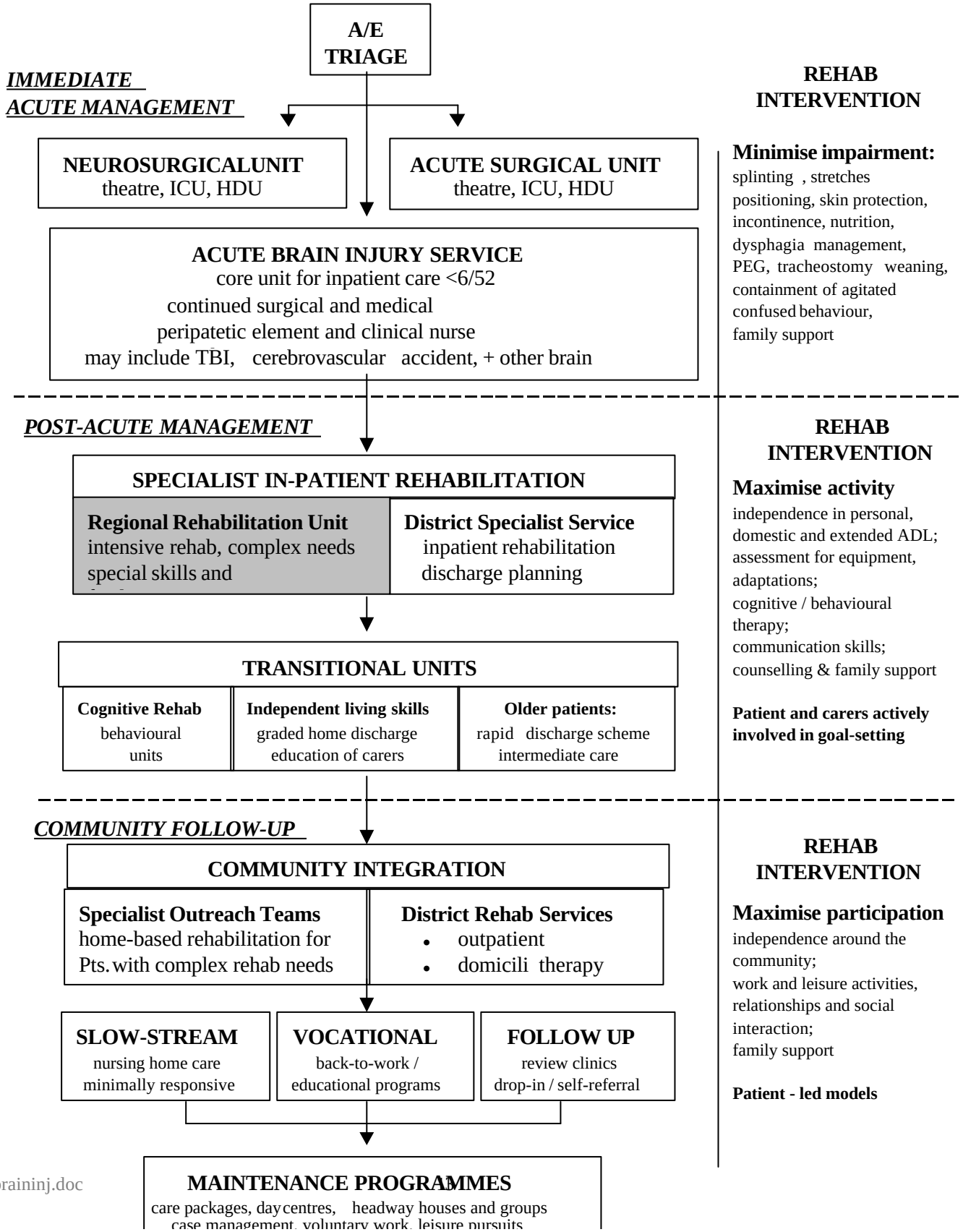
These groups require very different interventions from staff with different skills and training. Some services can be provided by general therapy departments, others require highly specialist skills. A range of different rehabilitation services is required.

This Appendix considers some models for provision of the spectrum of services for brain injury rehabilitation.

1.2 The different levels of rehabilitation services

Figure 3 summarises the different types of rehabilitation service that a patient may need to access following brain injury (shading denotes specialised service)

Figure 3: Rehabilitation after brain injury



1.3 Some principles of provision

1.3.1 Ageism and the approach to rehabilitation

Ageism is to be avoided, but it is important to recognise that old and young people have different needs and expectations of outcome and there is therefore a difference in approach between 'care of the elderly rehabilitation' and 'young adult rehabilitation'. The cut-off point at which it is appropriate to provide either of these approaches, however, is not determined simply by chronological age and should be a matter for judgement in individual cases.

For elderly patients, hospital is a dangerous place and rehabilitation towards independent function ability is often much more appropriately provided in the context of their own homes. In a Care of the Elderly setting, 'rehabilitation' means getting the patient out of hospital as soon as they can manage in the community, and continuing rehabilitation there. Since most are retired, social rehabilitation may be directed more towards leisure activities than work-related skills.

Young adults have goals beyond simply managing their basic daily care. They have years ahead in which to reap the benefits of functioning on a higher level. The long term cost benefit of achieving goals such as 'independent mobility with an energy-efficient gait pattern' or 'return to work' is worth the initial investment in effective rehabilitation. Rehabilitation to optimise function may require a range of hi-tech equipment and the skills and facilities of a specialised service that is lead by a consultant specialist in rehabilitation medicine, usually from a hospital base.

1.3.2 Home or hospital-based rehabilitation

Despite the recent vogue for community-based rehabilitation centred in the home, it is now apparent, that where there are needs for special facilities or input from many disciplines, rehabilitation may be more appropriately and cost-effectively provided in the hospital / unit setting on an in or day patient basis.

The site where rehabilitation is delivered therefore depends on the patient's needs:

- Hospital base – if they require special equipment or facilities, or the co-ordinated input of many disciplines, and can access transport to get to hospital
- Home based – if it is important that rehab is undertaken in a familiar environment

Rehabilitation in the third "community" phase of Figure 2 must be provided flexibly in the hospital or home setting as appropriate. The availability of transport services will determine this flexibility.

1.4 Organisation of rehabilitation services

With the current financial pressures on the NHS, managers face a real difficulty in trying to provide quality services on inadequate funding. It is recognised that the overwhelming and immediate pressures on the acute services may easily cause managers to overlook the chronic services. However, it is also clear that the acute agenda will flounder unless the support services are in place to avoid acute beds being blocked by avoidable admissions. The proposals put forward in this strategy therefore aim to provide rehabilitation in a cost-effective manner, which will move patients into the community, but with the level of independent function and support that will keep them there in the long term.

1.5 Networks and co-ordinated models for service management and provision

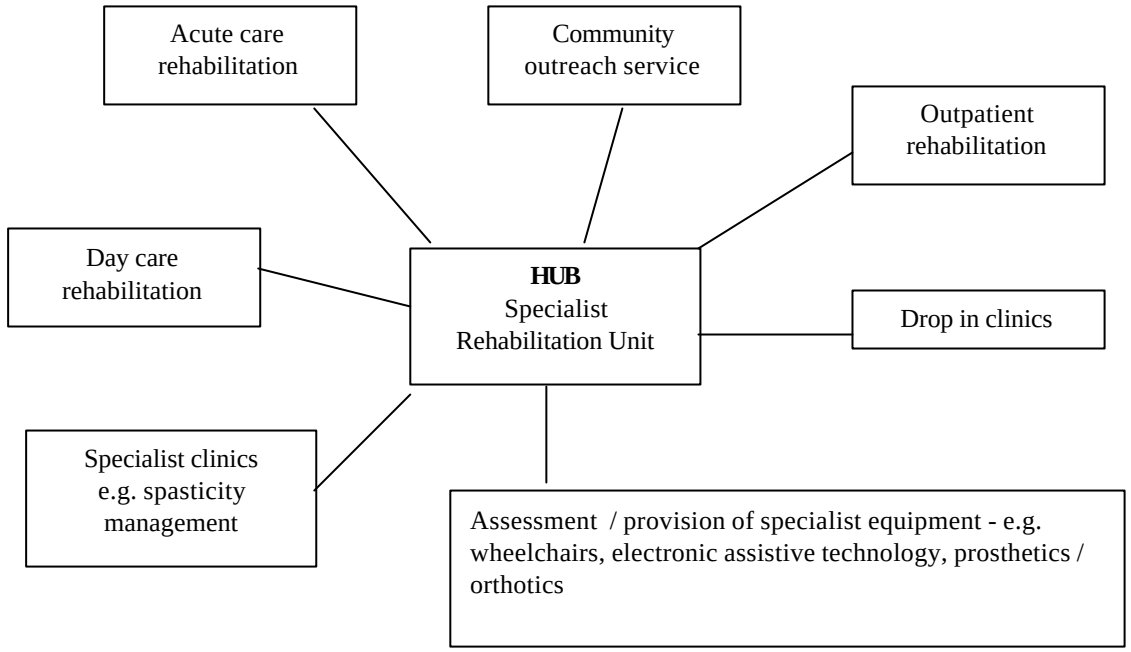
The number of patients needing each service at any one time is too small to provide all types of service in each district. A collaborative network of services set up across a region or several districts provides cost-efficient care, but to ensure that patients can move easily between them, collaborative commissioning arrangements must be in place. A central administration point for the network can provide efficient contracting and management, and one formalised network system is the 'hub and spoke' model which is shown to work effectively in the USA and some parts of the UK.

The hub and spoke model in this document refers to a concept, rather than a geographic plan set, and may be interpreted at various levels. Services are provided around a central hub or specialist rehabilitation unit. This hub provides a focus for administration, staff support, training and research (Figure 4). Close working links are maintained with outlying parts of the service - e.g. shared or rotating staff. Peripatetic community teams may keep their base in the hub unit, and travel out to patients in the community, or receive them for day-care in the main unit as required.

The advantages of the hub and spoke model are:

1. Decreasing administration and overhead costs by collecting several different teams together under one roof
2. Achieving critical mass in terms of staff – optimising balance of junior to senior staff, to reduce cost of duplicating senior staff, while maintaining adequate supervision for juniors in the different teams
3. Improved recruitment and retention – staff feel confident and well-supported
4. Development of clinical expertise as each team becomes expert in the use of techniques and procedures relevant to their own field of practice
5. Sharing of information and continuity of care between the hospital and community teams by use of common protocols and pathways
6. Cost-effective use of facilities, since services are not duplicated in each locality, but smooth referral paths exist to ensure that each patient has access to the service they require and the stage when they need it
7. A single point of contact for collaborative commissioning to cut down the number of different contracts and meetings. In high-cost/low volume contracting a single case more or less can cause a contract to over or under-perform. Collaborative commissioning and service provision helps to spread this risk

Figure 4: Hub and spoke model



1.6 Threats to the development of co-ordinated rehabilitation services

Boundaries at many levels conspire to confound effective development of co-ordinated services. These include:

- **Bureaucratic and funding boundaries**
  Prevent patient from accessing the service most appropriate to their needs at any one time

- **Split between different providers**
  The current split of service between the acute and community trusts leads to disjointed care and poor support for some of the rehabilitation professionals. Division of services into Adult and Care of the Elderly leads to inequality of service. Provision of specialised services for certain diagnostic groups can be an efficient way to deliver care, but provision must be made for patients who do not fit into any of the specialised categories

- **Split between health and social services**
  In different parts of the country there are different arrangements for sharing the burden of continuing care and rehabilitation between health and social services. Much time and effort is wasted in arguing over who is responsible for which part of a single patient's care

Whatever system is put in place for funding and provision of rehabilitation services must overcome these barriers in order to provide optimal care for this vulnerable group of patients.