Service Specification - Summary

Service Specification No.	D02/S/a
Service	Specialised Rehabilitation for Patients with Highly Complex Needs (All Ages)
Period	12 months
Date of Review	

This Service Specification Summary explains what is provided by the specialised rehabilitation service and how it is delivered, who the service is for, and how patients and their families/carers are involved. It also covers what should happen to support discharge from the service, and continue rehabilitation in the community or elsewhere.

WHAT IS THE SERVICE?

The specialised rehabilitation service works with patients of all ages who have disabling conditions and their families and carers in an active way to address all needs. The team, which includes doctors, nurses and therapists amongst other professionals, will have completed specialist training in rehabilitation, and is led/supported by a consultant trained and accredited in rehabilitation medicine or neuropsychiatry depending on the main rehabilitation needs of the patients being treated.

WHO IS THIS SERVICE FOR?

The service is aimed at patients with highly complex rehabilitation needs that are not able to be provided for by local services.

There is strong evidence that these patients make better long-term improvements when transferred quickly into specialised intensive rehabilitation services and that it is cost effective.

As well as having physical disability, people with complex disabilities may have difficulties with communicating; with thinking; and with behaving and interacting appropriately with others. They typically have a mixture of medical, physical, sensory, cognitive, communicative, behavioural and social problems, which require specialist input from a wide range of disciplines working together as a coordinated team.

The service is also for people with 'profound disability'; these are more severely affected patients who need help with all their basic care and will often require additional interventions such as management of their muscle tone, seating and postural support programmes. They may also be reliant on highly specialist equipment.

There are broadly three kinds of condition that may give rise to complex disability and in summary these are;

- **Sudden onset conditions** such as acquired brain injury, spinal cord conditions and peripheral nervous system conditions.

- **Progressive and intermittent conditions** such as neurological and neuromuscular conditions (e.g., multiple sclerosis, motor neurone disease, muscular dystrophies), and severe musculoskeletal or multi-organ disease

- **Stable conditions that are with or without degenerative change** such as congenital conditions (e.g. spina bifida, cerebral palsy)

WHAT DOES THE SERVICE PROVIDE?

The key aim of the service is to provide rehabilitation for patients with complex needs in order to assist them to achieve their maximum potential for physical, cognitive, social and psychological function. It includes a combination of individual and group-based treatments to support appropriate social interaction, communication, life and work skills. The service aims to improve participation in society and overall quality of life for all patients.

It also aims to assist family members to understand about the effects of the injury, and effectively to train them by including them as part of the rehabilitation team.

Specialised rehabilitation services fall broadly into four types of programme:

- for people with profound and complex physical disability

- for those who are independently mobile but have severe cognitive impairments (that is, in their thinking and reasoning abilities, and with memory and attention) and/or behavioural/emotional needs

- to assist people to rejoin their community and/or return to work/education and homemaker/family roles

- Programmes for children/adolescents (including 16-18 year olds) or young adults who require specialised rehabilitation while in school or on-going education. Some children/adolescents may have particular needs with regard to safeguarding and consent.

Patient goals will vary according to the likely route towards recovery and the stage of their condition. Services may be provided along three main (often overlapping) pathways:

- **Restoration of function** (e.g. for those recovering from a 'sudden onset' or 'intermittent' condition) - where goals are focused not only on improving independence in daily living activities, but also on participatory roles such as work, parenting, etc

- **Disability management** (e.g. for those with stable or progressive conditions) - where patient/family goals are focused on maintaining existing levels of functioning and participation; compensating for lost function (e.g. through provision of equipment / adaptations); or supporting adjustment to change due to deteriorating physical, cognitive, and psychosocial function.

- **Neuro-palliative rehabilitation -** where the goals are focused on symptom management and interventions to improve quality of life during the later stages of a progressive condition or very severe disability

The service is primarily offered as a time-limited, in-patient residential programme. Many people with complex needs require programmes that last 3-6 months. Occasionally a longer period of rehabilitation is required, e.g. for severe neurological injury, and this is highly cost-effective for some patients, particularly young patients with catastrophic brain injuries.

Some patients will require repeated episodes of rehabilitation planned over a period of time, with intermittent periods of consolidation.

HOW IS THE SERVICE PROVIDED?

The service is commissioned by NHS England on a Regional basis and is provided in identified Specialised Rehabilitation units, each serving a catchment population of 1-3 million people.

Due to the limited number of such units, patients may need to be treated outside their local area. Specialised Units communicate throughout with Clinical Commissioning Groups (CCGs) in relation to their patients being treated, and discuss which services will be required once the patient is discharged.

Each unit meets minimum staffing levels as laid down by the Royal College of Physicians and the British Society of Rehabilitation Medicine, and has specialist equipment and facilities. The multidisciplinary team works together towards an agreed set of goals for each patient. The units vary in the specific services they provide, but all are required to comply with nationally agreed standards.

WHO IS NOT INCLUDED IN THIS SERVICE?

The following are usually excluded:

- Long-term care/support (such as that offered in specialist nursing homes or slower stream rehabilitation facilities over periods of 12 months or more)
- Purely community/out-patient programmes
- Children who may have complex rehabilitation needs but also require management in the context of a paediatric neuroscience centre.
- Certain conditions that may be better treated in other specialist services e.g. complete spinal cord injury (require dedicated spinal injuries unit),
- Very severe challenging behaviour or forensic problems
- Those requiring longer detention under Mental Health Act
- Medical instability that would require an acute general hospital setting
- People who are unwilling or unable to engage in rehabilitation.

WHAT ELSE MAY BE NEEDED?

These specialised services may rely on a range of other hospital-based services, for example:

- Imaging and diagnostic services
- Expertise from other medical specialties including neurology, neurosurgery, neuropsychiatry, stroke services, cardiovascular services, PEG and tracheotomy services, trauma and orthopaedics, maxillary facial services, paediatrics
- Acute emergency medical and surgical cover out of hours.

HOW ARE SERVICE USERS AND CARERS SUPPORTED?

Patients and family/carers should be engaged in all relevant aspects of the rehabilitation process. Rehabilitation should be a collaborative process between the rehabilitation team and the patient and family/carers.

Family/carers will receive individual support (including psychological support / counseling / psychotherapy); group support including psychological support and peer support through facilitating contact with other family/carers including those of ex-patients; education about the condition and its effects; support/training with managing particular difficulties (physical /cognitive/

behavioural); support in considering their own role vis-à-vis other (paid) care and support services; and support with developing coping strategies.

Information should be provided in a variety of formats to enable it to be available to all who need it, including those with communication and cognitive difficulties and should include:

- up-to-date information about the service provided to patients and family/carers by the rehabilitation unit (in written and spoken form, and via its website);
- information and advice about disability benefits and signposting to relevant helplines, etc
- information about further rehabilitation services, relevant community services and specialist and other support groups;
- information about useful publications produced by the voluntary sector (including some copies kept in the unit)
- signposting to relevant helplines; and to information and signposting services themselves.

WHAT ABOUT DISCHARGE FROM THE SPECIALISED UNIT?

Discharge planning should start immediately following multidisciplinary assessment within the unit and the family and other carers should be involved in discharge planning throughout.

When the patient leaves the specialised unit, their care transfers to other groups who provide services either in the community or within other parts of the hospital. All patients will have a care manager and care plan, and a planning meeting will take place for rehabilitation staff, patient, carers and family.

A discharge report will be produced in a language accessible to all and will be given to the patient, and family/ carers where appropriate. This report will include signposting to support services including further rehabilitation services and voluntary organisations, as well as practical information and assistance for carers. The GP will receive a copy of the report.

Family/carers should receive advice and/or training with respect to managing ongoing needs, including physical management, dealing with cognitive and behavioural problems and communication needs

It will be important that there are appropriate coordinated services in the community, to which the patient can be promptly transferred - particularly to enable the gains made as an inpatient to be consolidated.

HOW IS THE SERVICE MONITORED?

Service providers report activity levels and outcomes for all their patients to a national dataset for specialised rehabilitation. This covers: response times / waiting times for assessment; admission etc.; length of stay, and discharge destination. It also identifies outcomes using standardised measures including functional assessment measures; reductions in requirements for ongoing care and costs in the community; attainment of individual goals; patient & family/carer satisfaction; and, where appropriate, quality of life tools; measures of community integration, and workability.