ResearchSummary

National Institute for Health Research

Rehabilitation services for long term neurological conditions: what works and what is available?

Over a million people are treated for a head injury each year and several million have progressive neurological conditions such as Parkinson's disease or multiple sclerosis. Many of them have complex needs requiring specialist rehabilitation and support. Meeting these needs is one of the standards of the National Service Framework for Long Term Neurological Conditions (DH, 2005). However, the provision of specialist neurological rehabilitation services remains patchy and little is known about how they are organised and delivered.

This research summary is based on a literature review and mapping exercise led by Professor John Gladman at the University of Nottingham, on behalf of the NIHR Service Delivery and Organisation Programme (SDO) on specialist rehabilitation services for people with long term neurological conditions. It discusses the scope and structure of existing services, what we know about their effectiveness and how the current gaps in our knowledge might be filled in future.

It will be of interest to anyone involved in delivering primary, secondary or social care services to people with neurological conditions, researchers with an academic interest, and interested members of the public.

Key findings

- Rehabilitation services for people with long term neurological conditions vary widely in terms of focus, type of provider and geographical location.
- Services tend to be focused on diagnosis and early management. During these stages, people with stroke have better access to services, and these services have been well-evaluated.
- Services for long term conditions are more limited. They tend to be focused on specific conditions such as multiple sclerosis and reliant upon the charitable sector.
- Service users and clinical staff want patient-centred services which are easier to access and better integrated with other provision.
- Beyond acute stroke units, we have little knowledge of which service models are most effective or why. This is largely due to a lack of sustained funding and a weak research infrastructure.
- Research could be strengthened in future by:
  - establishing national networks of specialist providers and comparing results
  - requiring all new services to set up evaluation processes so that this happens as an automatic and ongoing process.

The Service Delivery and Organisation Programme is part of the National Institute for Health Research

Background

Neurological conditions affect around 10 million people in the UK. Over a million are treated for a head injury each year and several million have progressive conditions such as Parkinson's disease or multiple sclerosis. Neurological conditions account for 20% of acute hospital admissions and are the third-most common reason for seeing a GP. While many of these do not have long term implications, an estimated 350,000 people need help with daily living because of a neurological condition and 850,000 people care for someone with a neurological condition (DH, 2005).

The needs of this large group of people are not being adequately met at present. Neurological conditions cannot be prevented or cured (with the exception of stroke, where preventive action can be taken). Service delivery therefore focuses on optimising the health and wellbeing of those affected, through rehabilitation and support. Recognising the shortfall in provision, the National Service Framework (NSF) for long term neurological conditions (DH, 2005) placed a number of requirements on health and social services, with the aim of providing responsive, flexible and person-centred services.

However, the NSF did not recommend an optimum model of service delivery. This reflected the lack of information available about different service models and their effectiveness. The study by Gladman *et al.* (2007) takes the first step towards filling these knowledge gaps, by mapping out the range of services currently available and scoping out the priorities for future research.

The study had two aims.

1. **To identify and describe existing service models for people with long term neurological conditions** – this was achieved through a 'mapping study' to develop and test a taxonomy of service models.
2. **To examine the evidence base for their effectiveness and cost-effectiveness** – this was achieved through a systematic review of the literature on rehabilitation services for people with long term neurological conditions.

Definitions used in the report

Long term neurological condition: condition resulting from disease of, injury or damage to the body's nervous system (the brain, spinal cord and/or their peripheral nerves) which will affect the individual and their family for the rest of their lives. Includes sudden onset conditions such as stroke, intermittent conditions such as epilepsy, progressive conditions such as Parkinson's disease, and stable neurological conditions in which needs change due to development or ageing (as defined in the NSF for long term neurological conditions).

Rehabilitation: an active educational and problem solving process that focuses on the patient and which aims to minimise the somatic and emotional distress facing the patient, their family and others affected by the condition (after Wade and de Jong, 2000).

Specialist rehabilitation service: rehabilitation undertaken by a multi-disciplinary team with special expertise in the condition of interest, for example as evidenced by specialist qualifications. This definition excludes generic primary, intermediate or secondary health and social services, although they are all involved in supporting people with long term neurological conditions.

Practical findings

1a. Findings from the service mapping

Services for people with long term neurological conditions vary widely in terms of their scope and availability across the country. **Table 1** shows the range of services identified in the study. **Maps 1** and **2** show where these services were available in 2007.

The key points to note are that:

- Not all rehabilitation expertise is found in specialist services. Many general services – in primary care, secondary care and social services – provide rehabilitation. So it should not be assumed that specialist services are necessarily better than non-specialist services (unless there is evidence to show that this is true, as is the case for stroke units).
- People with stroke generally have greater access to acute services than those with other neurological conditions (for example, traumatic brain injury). However services aimed at helping people with stroke reintegrate into the community are less well developed.
- Services are primarily focused on the early stages of diagnosis and management, in hospital or acute provision. Services which address longer term needs, including issues around mental well-being and community reintegration, are more limited.
- Statutory specialist services tend to be based in cities, with better provision for stroke (which is common) than for other conditions. In one case, metropolitan and county council boundaries meant that one city had two separate stroke services.
- Provision in rural areas appears to be poor. Some areas are developing 'hub and spoke' models in which specialists provide outreach services to community hospitals.
- Community services appear to be developing rapidly, while the number of hospital beds is reducing. This appears to be driven by the reorganisation of primary care trusts and the introduction of the NSF. Community services are attracting skilled staff, which might challenge hospital-based services in future. Many community services are being delivered by the voluntary and private sectors in purpose-built facilities.
- There is an unexpectedly large number of non-statutory services. Charities feel they are 'filling in the gaps' that statutory services do not meet. This could be seen as evidence of a historical failure of statutory services to meet clinical needs. However, some voluntary and private sector services are contracted to the NHS rather than being funded by charitable donations or insurance claims.
- There is some joint working across professions, however this tends to be a result of initiative and goodwill rather than strategic commissioning. For example in one area a specialist nurse funded by primary care runs a stroke prevention clinic in secondary care.
- Innovations in the delivery of rehabilitation services are more prominent in the non-statutory sector, perhaps as they are better placed to identify unmet needs. However new multi-disciplinary networks and social enterprise schemes can be found in statutory provision. In one area a web-based information resource aims to promote continuity of care and better access to services.

Table 1 Rehabilitation service models

This typology was developed from interviews with medical staff and service users. The 25 service patterns accommodate all of the services identified nationally. They each contain a combination of some or all of nine defining features of rehabilitation services, as identified by medical staff and service users.

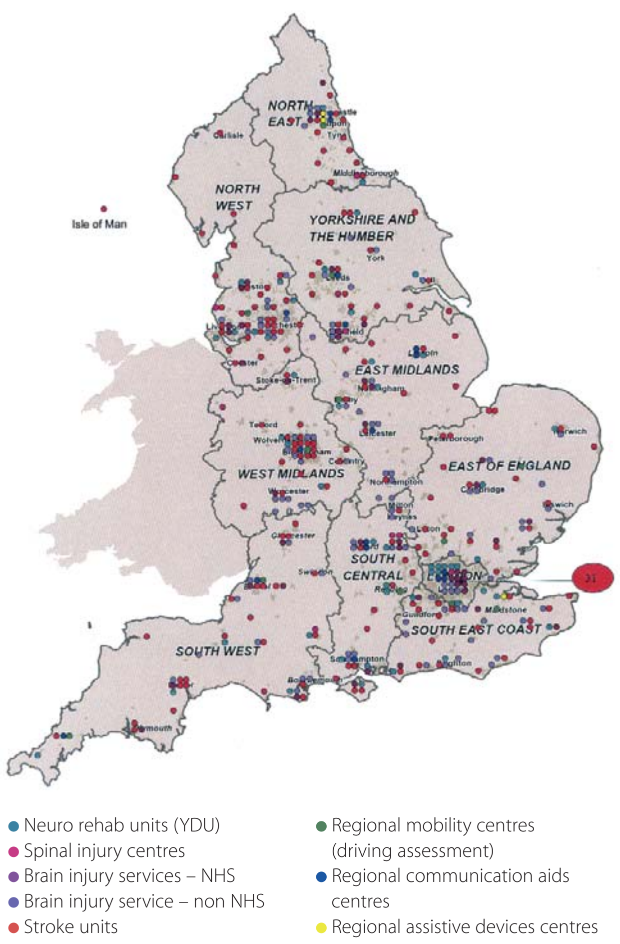
	Service model	Rehabilitation phase and overview of services
1	Specialist inpatient acute unit	*Acute phase – usually initial few days or weeks:* Based in acute hospitals. High nursing levels. Provides nursing care and therapy to reduce consequences of immobility, confusion, swallowing and breathing difficulties. Assesses need and identifies rehabilitation goals.
2	Non specialist acute unit	
3	Surgical acute unit	
4	Specialist inpatient rehab unit	*Acute and sub-acute phase:* Mainly for patients with neurologically-disabling disorders. Typically offers review or respite following a period of acute care. Supports transition between hospital and community; with emphasis on personal care and basic living skills. Services may be provided over period of several weeks.
5	Specialist inpatient combined (acute and rehab) unit	
6	Inpatient services	

Table continued overleaf

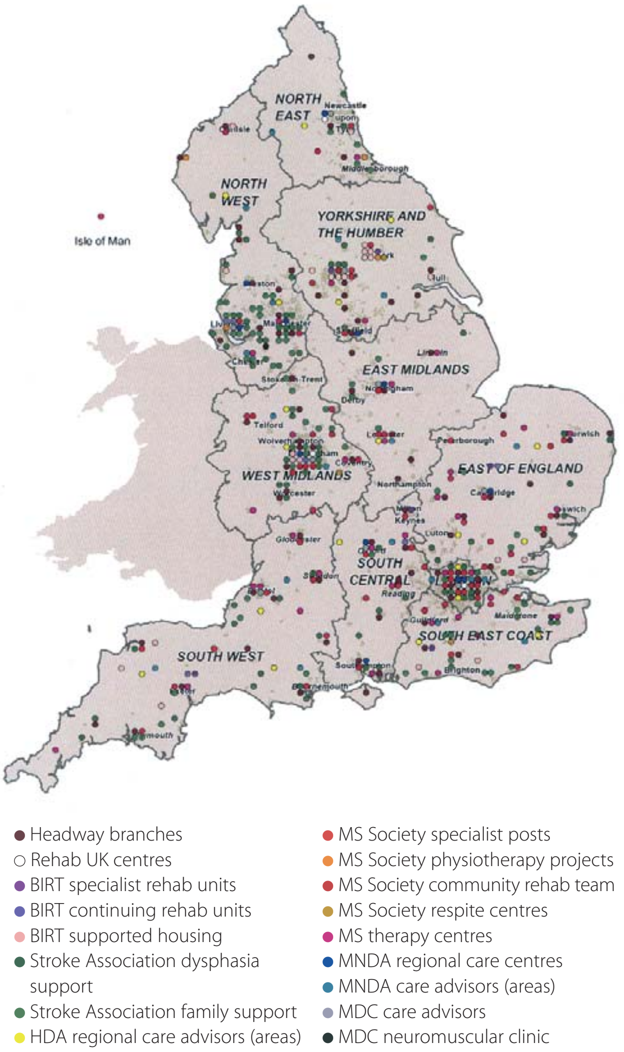
Table 1 Rehabilitation service models ***continued***

	Service model	Rehabilitation phase and overview of services
7	Condition specific specialist nurse	*Acute, sub-acute and chronic phase:* Run by individuals not teams (however can include leaders of 'virtual' teams). Patients referred soon after diagnosis; contact continues indefinitely. Specialist nurses provide support and education as well as co-ordinating other services. Focus on people in their own homes, often alongside other community rehabilitation services.
8	Condition specific specialist therapist	
9	Case management	
10	Third sector condition specific nurse	
11	Third sector condition specific therapist	
12	Outreach rehabilitation (NHS/PCT) team	*Sub-acute and chronic phase:* Includes outreach rehabilitation teams such as hospital at home services, early discharge services, specialist community rehabilitation teams in health and social services. Can be condition-specific (e.g. traumatic brain injury or stroke) or open to people with any neurological condition. Typically offer interdisciplinary management aimed at promoting activity, participation and wellbeing.
13	Outpatient services – statutory sector	
14	Specialist community rehabilitation (NHS/PCT) team	
15	Specialist community rehabilitation – private sector	
16	New innovative models	*Sub-acute and chronic phase:* Covers a range of services, for example a social enterprise scheme which operates like an agency to supply specialist therapists from all over the UK to infill identified gaps in service provision; a one-stop nurse-led brain injury outpatient clinic which accepts self-referrals; and a collaborative venture between two NHS consultants to provide an outreach service to people with motor neurone disease in rural areas.
17	Regional specialist centre (driving, communication, assistive devices)	*Chronic phase:* Mobility centres, communication aids centres and assistive devices centres offer assessment, advice, training and loan or sale of equipment where necessary.
18	Statutory residential facility for respite or long term care	*Chronic phase:* For people with long term rehabilitation and residential care needs. Few statutory facilities; growing number of private sector services. Offer cross-cutting services for patients with high nursing dependency. Focus on mobility issues and activities for social inclusion.
19	Private or third sector residential rehabilitation facilities, respite or long term care	
20	Multi-disciplinary clinic	*Chronic phase:* Includes multi-disciplinary clinics such as movement disorders clinics or problem-focused clinics (e.g. spasticity) where community based patients attend for specialist intervention or assessment by a team of healthcare professionals including nurses, doctors and therapists.
21	Outpatient services – private sector	*Chronic phase:* Clinics or services in the private sector, e.g physiotherapy.
22	Specialist outpatient services – statutory sector	*Chronic phase:* For patients in the community. Includes specialist outpatient therapy services. Patients referred are medically stable, living in the community and undertaking a specific programme of rehabilitation. Focuses on improving mobility, increasing independence and promoting participation, e.g. in returning to work or education.
23	Specialist outpatient services – private sector	
24	Third sector rehabilitation	*Chronic phase:* Includes structured daytime activity, family support and advocacy or rehabilitation to improve mobility, increase independence and promote activity, participation and wellbeing.
25	Third sector social, patient and carer support	*Chronic phase:* Often provided by condition-specific charities or service user groups. Includes support groups, self help groups, outreach and respite services and advice and telephone information services. For carers, patients and family members. Can include advocacy and benefits help.

Map 1 Statutory specialist services and organisations in England



Map 2 Non-statutory specialist services and organisations in England



Underlying maps produced by the Department of Heath via the Pan Government Agreement with the Ordnance Survey

1b. Views of service users and medical staff

The study gathered the views of more than 200 service users, medical staff and commissioners of services.

Among service users, acute care services were spoken of highly, though they felt longer term care was severely lacking. People wanted easier access to services, and particularly valued clinical expertise and a service which treated them as an individual. People felt that lack of co-ordination meant that there was no continuity of care when services were needed from a range of providers. The criteria for accessing services could be too inflexible. For example, a woman with multiple sclerosis who needed adaptive rehabilitation was refused therapy because the service criteria required her to be able to get better.

Service providers echoed service user concerns about a lack of ongoing and long term care and a lack of co-ordination between services. They were also concerned about a shortage of psychotherapeutic and social care staff, and a lack of resources in relation to hospital beds, aids and appliances, and community provision.

Service commissioners recognised the difficulties facing service users in rural areas, but observed a conflict between specialist services which tend to be centrally located and which are better able to meet clinical need, and locally provided services which are better able to address social needs (for example reduced travelling distance). They also identified a lack of consistency in the way that specialist services can be accessed, because there are no formal clinical pathways or guidelines currently in place.

2. Findings from the literature review

The literature review highlighted a significant lack of research on rehabilitation services for all conditions except stroke. This is partly due to methodological problems – for example, inconsistency in defining ‘rehabilitation services’ has led to a lack of measurement. It is also due to the lack of a research infrastructure and investment.

Stroke services have been most thoroughly researched. Randomised controlled trials (RCTs) and systematic reviews have demonstrated the benefit of organised inpatient care in a specialist stroke unit in comparison with the care received on general medical wards. Studies which followed up patients a year after being discharged also show positive outcomes, though there is no clear preference for any particular service model. This evidence of effectiveness is not backed up by good cost-effectiveness studies.

The evidence on conditions other than stroke is essentially absent, rather than negative:

- Few studies have been undertaken for people with **traumatic brain injury** and none compare different models of inpatient care. A small number of studies show that patients with post-traumatic amnesia benefit from routine follow-up contact to give information and advice. A subgroup of patients with moderate to severe injury appear to benefit from a higher level of intervention, and may not present themselves unless routine follow-up is provided. The cost effectiveness of doing so is not known.
- No robust studies have evaluated acute or sub-acute care for people with **spinal cord injuries**.
- The studies for **Parkinson’s disease** have mainly assessed nurse specialists compared to non-specialist nursing care. These show that patients are more satisfied with specialist nurse care, but there is no evidence of a difference in health outcomes. There is also little difference in terms of cost.
- For **multiple sclerosis**, a number of small studies comparing brief periods of inpatient rehabilitation with community provision show a mixed picture, and there are no useful economic studies.
- Few studies looked at **longer term** provision.

Conclusions

- There are a number of models of rehabilitation provision for long term neurological conditions, delivered by specialists and non-specialists across the statutory, voluntary and private sectors.
- Access to services varies considerably depending on a person’s condition, where they live and what stage of care they are at. Services tend to be concentrated in cities, are more prevalent for stroke, and are focused on the early stages of managing the condition.
- Service users value the acute care that is available, and services which are person-centred and provide clinical insight and expertise. Along with staff and commissioners, they feel that services are currently too difficult to access, particularly for people in rural communities, and that different aspects of service provision are not sufficiently integrated to offer real continuity of care.
- Evidence from research suggest that specialist stroke units are more beneficial for patients than general medical care. However, insights into particular service models for stroke or other conditions are not yet available. That said, the literature is consistent with the view that rehabilitation is beneficial. It also reinforces the commonly held view that services should be accessible, patient-centered, long term, joined up and focused on encouraging participation in community life.
- A lack of information means that it is difficult to draw any conclusions on cost-effectiveness at present.
- There are a range of barriers to conducting research, including a lack of research infrastructure and investment, the lack of a clear terminology to describe and classify services, and the difficulty of describing and quantifying some outcomes (for example in relation to participation in mainstream community life). There are also practical challenges to research, namely the relatively small numbers of patients with certain conditions, and the ethical issues of carrying out a comparison studies where participants are randomly allocated to a service or to a ‘no treatment’ alternative.

Recommendations and future research

To give commissioners sufficient information to make decisions about future service provision, the report recommends establishing a network of rehabilitation services with the aim of developing a stronger research infrastructure. This could be done in two ways:

1. Through the development of national networks of providers of services for long term neurological conditions, as already exist for other conditions such as cancer. Within a network, services could compare, contrast and benchmark their provision. Then, more rigorous comparison studies could be carried out, for example between service providers and between those receiving a service and those waiting for a service.
2. By ensuring that new services and developments are evaluated before they become too assimilated into local provision to make a comparison study possible. This requires widespread acknowledgement of the absence of an evidence base and a policy emphasis on the importance of evaluation.

Such developments could help to fill a number of specific research gaps, in particular:

- reliable information on the incidence and prevalence of neurological conditions
- well-designed RCTs and economic evaluations of services for people with conditions other than stroke
- exploration of the extent to which long term needs are identified, reviewed and addressed
- exploration of continuity issues when people transfer between service providers and stages of rehabilitation
- evaluation of different service models:
  - participation-orientated services (for example involvement in work, leisure and social activities
  - innovative delivery methods (for example telephone and web methods, use of volunteers)
  - new services such as vocational rehabilitation services
  - home-based alternatives to hospital care.

Research into the following specific areas is also recommended:

- For **stroke**, good cost-effectiveness studies to compare models of community-based rehabilitation and evaluate services which address longer term health issues.
- For **traumatic brain injury**, studies to evaluate models of community rehabilitation; provide better measures of participation in the community; compare different models of inpatient care and examine cost effectiveness and benefits (social and personal as well as health benefits).
- For **Parkinson's disease, spinal cord injuries** and **multiple sclerosis**, robust studies to determine the costs and best methods for organising and delivering rehabilitation services, including community-based services and therapeutic interventions.
- For **epilepsy**, further evaluation on the outcomes and cost of specialist nurse provision.
- **Qualitative research** on service user experiences and the rehabilitation context to ensure that future services are relevant and that future evaluations involve service users and capture the extent to which their needs are met.

About the study

The purpose of the study was to identify and describe existing models of specialist neurological rehabilitation services provided to people with long term neurological conditions and to examine the evidence base for their effectiveness and cost effectiveness.

There were two stages to the study:

1. A mapping exercise with local experts to identify models of 'specialist' neurological rehabilitation for people with neurologically based activity limitation in the UK. More than 200 service users, providers and commissioners were interviewed, mostly by telephone, using a semi-structured interview guide. They were asked in detail about the specialist neurological services they commissioned, delivered or received. From their responses, a taxonomy of service models was developed and used to identify similar service models elsewhere.
2. A systematic review of the national and international literature on specialist neurological rehabilitation, its organisation and delivery. A search strategy was developed which would identify both quantitative and qualitative reports in order to provide the fullest picture of service delivery and organisation as well as effectiveness. A total of 5104 articles were considered for inclusion, 4728 from electronic databases and 376 references from hand searching grey literature. The studies that met the criteria for inclusion were reviewed by two panels of reviewers – one for the quantitative literature (153 papers) and one for the non-quantitative (118 papers).

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Further information

The full report, this research summary and details of current SDO research in the field can be downloaded at: www.sdo.nihr.ac.uk

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Feedback

The SDO Programme welcomes your feedback on this research summary. To tell us your views, please complete our online survey, available at: www.sdo.nihr.ac.uk/researchsummaries.html

About the SDO Programme

The Service Delivery and Organisation Programme (SDO) is part of the National Institute for Health Research (NIHR). The NIHR SDO Programme is funded by the Department of Health.

The NIHR SDO Programme improves health outcomes for people by:

- commissioning research and producing research evidence that improves practice in relation to the organisation and delivery of health care; and
- building capacity to carry out research amongst those who manage, organise and deliver services and improve their understanding of research literature and how to use research evidence.

For further information about the NCCSDO or the NIHR SDO Programme visit our website at www.sdo.nihr.ac.uk or contact:

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Edited by Rachel Pope   Design: signgraphicdesign.co.uk

Disclaimer

Addendum

This document was published by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) research programme, managed by the London School of Hygiene and Tropical Medicine.

The management of the Service Delivery and Organisation (SDO) programme has now transferred to the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Prior to April 2009, NETSCC had no involvement in the commissioning or production of this document and therefore we may not be able to comment on the background or technical detail of this document. Should you have any queries please contact sdo@southampton.ac.uk