

## Integrated services for people with long-term neurological conditions: evaluation of the impact of the National Service Framework

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Many people with long-term neurological conditions (LTNCs) require support from a range of services, but these services do not always work in a joined-up way. The National Service Framework (NSF) for Long-term Neurological Conditions recognised the need for an integrated approach to service delivery. Our study explored what helps or hinders service integration and identified three types of service that promote continuity of care. We then conducted a survey of all English Primary Care Trusts (PCTs) to assess the initial impact of the National Service Framework on integrated service provision.



### Key findings

- There is little published evidence about the cost effectiveness of integrated services for people with LTNCs, or what works well from the point of view of people using them. Outcome measures that address personal choice, empowerment, or the experience of continuity of care are largely absent from the literature.
- Our interviews with people with LTNCs identified a number of factors that can promote continuity of care, including:
  - having a single person or team co-ordinating support across boundaries and providing advocacy where necessary
  - this person or team having specialist knowledge of LTNCs and available systems of support
  - flexibility in how, when and where services and support are delivered
  - long-term involvement
  - proactive monitoring and/or follow-up
- We identified three types of service that have these elements and so can promote continuity of care for people with LTNCs:
  - community interdisciplinary neurological rehabilitation teams
  - nurse specialists
  - proactive, holistic day opportunities services

- However, access to these services is frequently compromised by restrictive eligibility criteria, ill-defined pathways and a lack of availability or capacity locally.
- Neurological charities and other voluntary sector organisations play a key role in improving access and promoting continuity of care.
- Our benchmarking survey of English PCTs showed that there is considerable variation in the availability of services for people with LTNCs.
- The implementation of the NSF for LTNCs has been hindered by competing policy, organisational and financial priorities.

## Background

In 2003, it was estimated that there were 10 million people in the UK living with a neurological condition that had a significant impact on their lives. Many people with long-term neurological conditions (LTNCs) require support from a range of services, but these services are not always delivered in a joined-up way.

The National Service Framework for LTNCs (2005), set out 11 Quality Requirements for LTNCs services; the theme of integration ran throughout. However, there was little information about how to achieve integration, or how to evaluate whether the desired outcome of integration (continuity of care) had been achieved.

Our study set out to explore what helps or hinders service integration and identified three types of service that promote continuity of care. We then conducted a survey of all English PCTs to 'benchmark' the initial impact of the NSF on integrated service provision.

## Findings

### Existing literature

Our review of existing literature on integrated models of care for people with LTNCs found that the evidence base was weak regarding: the impact and costs of integrated models of care for people with LTNCs; and what is needed to make these models operate well. Moreover, the choice of outcome measures for many of the studies was limited. Measures that addressed issues of personal choice, empowerment, or the experience of continuity of care were largely absent.

In light of the lack of existing evidence on the outcomes of integrated services for people with LTNCs, we chose to make the experience of people with LTNCs a major focus of our own case study research.

### Services that promote continuity of care for people with LTNCs

The optimum outcome we would expect to find from the provision of integrated services is continuity of care. Bringing together the views and experiences of the people we interviewed in our six case sites, we identified three models of good practice for integrated service delivery, each of which contributed to people with LTNCs experiencing continuity of care. These were:

- **Community interdisciplinary neurological rehabilitation teams (CINRTs)**

People in receipt of services from a CINRT (rather than lone therapists or out-patient hospital services) tended to have improved experiences of continuity of care. Ongoing access to community rehabilitation was important for the people we interviewed, to generate improvements and also to maintain physical functioning and psycho-social well-being. The interdisciplinary way that team members worked, undertaking joint assessments and interventions and sharing case information, meant people with LTNCs received a seamless service from a wide range of professionals. Responsive, flexible services were valued most, particularly where interventions could be provided at a time and location convenient for the person with the LTNC and their families or carers. When social workers and health care professionals worked in an integrated way in these teams, a more holistic approach could be taken and cross-sector boundaries became less problematic.

- **Nurse specialists**

This model is highly valued by people with LTNCs, their families and carers, and the professionals and volunteers working with them. Where the model worked most effectively, nurse specialists acted as key-workers, engaging in active care co-ordination and advocacy to ensure that people with LTNCs could access a broad system of joined-up support. Nurse specialists were often people's first port of call. Their specialist knowledge and accessibility meant that they were able to answer questions, allay fears and access further services as the need arose.

● **Proactive, holistic day opportunities**

Services that offered peer support, social and leisure opportunities, as well as access to meaningful activity and/or learning and employment opportunities were highly valued. These provided a focal point for care co-ordination as well as supporting people to build confidence and enjoy social activities. Those which specialised in meeting the needs of people with a specific LTNC were felt to be particularly valuable. For many people, these services were key to maintaining quality of life and feeling like a valued member of society. For many people, these services were key to maintaining quality of life and feeling like a valued member of society.

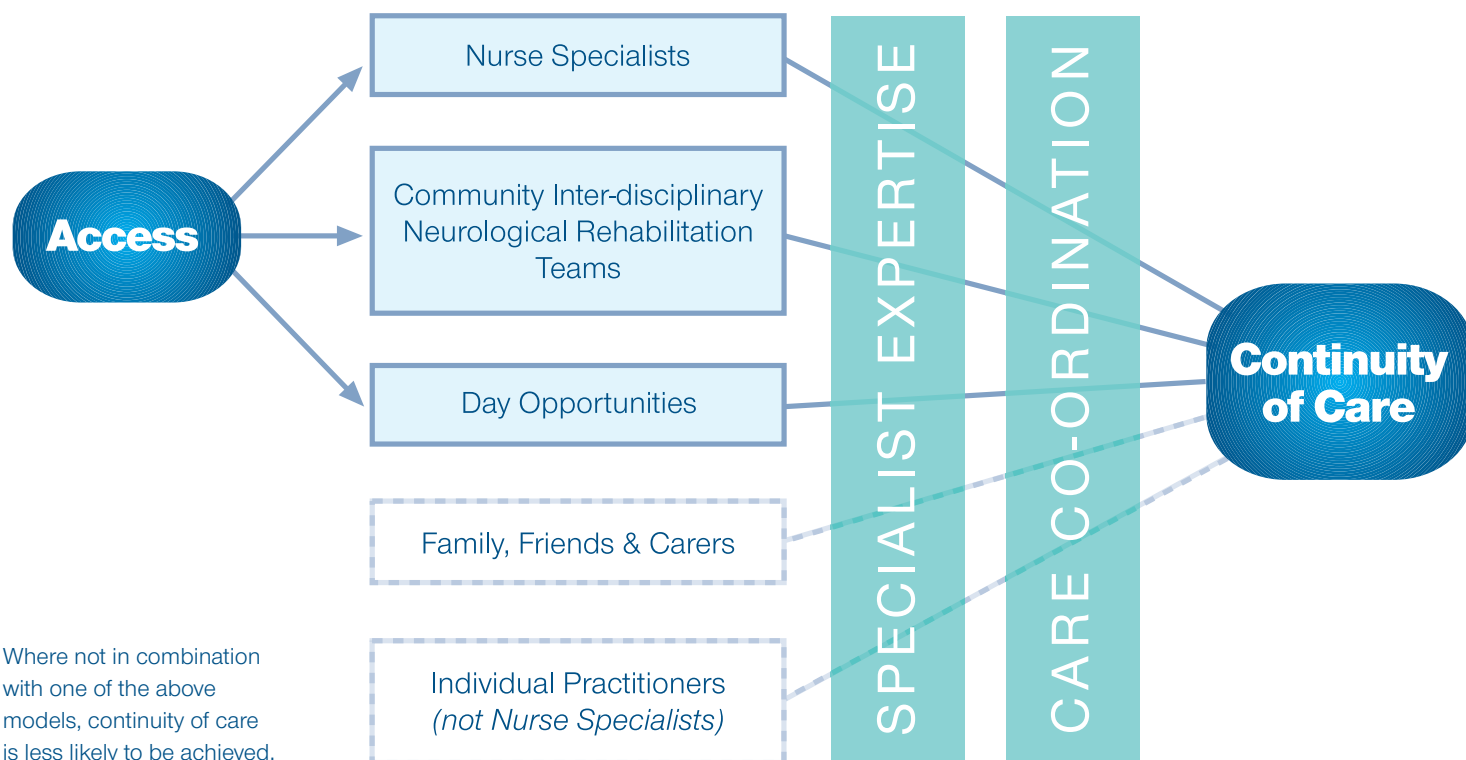
**Voluntary sector agencies**

Voluntary organisations were important in the delivery, planning and commissioning of service models, as well as providing care co-ordination and access to condition specific information. Nevertheless, there is considerable variation in their influence, both geographically and by condition. The degree to which statutory services actively collaborate with voluntary sector agencies also varies considerably between locations.

**Access**

Timely access to support was central to the experience of continuity of care. However, this was frequently compromised by a lack of local availability or capacity of services, restrictive eligibility criteria, referral anomalies and pathways that were ill-defined and unclear to people with LTNCs and professionals. Evidence from our case studies, and from the benchmarking survey (see below), suggests that not all people with LTNCs currently have access to one or more of the three models that promote continuity of care. Where people do not, their main source of support may instead be an individual professional without a cross-sector care co-ordinating role (such as their neurologist) or without a neurological specialism (such as their GP). It is here that discontinuities can arise. Evidence from our case studies suggests that in such circumstance the onus for care co-ordination often falls to the person with the LTNC, their families or carers. This can put them under considerable pressure and may result in their feeling let down by, or lost to, the system.

**Representation of models and processes influencing Continuity of Care**



**Benchmarking survey of English PCTs**

Results from our national benchmarking survey reinforced findings from earlier phases of the research. Nearly half way through the ten-year implementation period of the NSF for LTNCs, only half of PCTs had a written action plan for implementation and very few had carried out their plans. The models we had identified as important were found across PCT areas, but there were noteworthy gaps, geographically and in the conditions covered. For example, based on responses from 118 PCTs:

- **CINRTs** – 73 percent of PCTs reported having one or more CINRTs.
  - Just under half of PCTs (47%) reported CINRTs covering all LTNCs.
  - Where a team covered only a single condition, brain injury was the most common condition reported.

- **Nurse specialists** – 93 percent of PCTs reported having one or more nurse specialists.
  - 79 percent of PCTs reported having Parkinson's Disease nurse specialists, 78 percent Multiple Sclerosis nurse specialists, compared with,
  - 50 percent for epilepsy, 9 percent for brain injury.
- **Pro-active day opportunities** – 65 percent of PCTs reported having one or more of these services.
  - While condition specific day opportunities services were favoured by participants in our case study, most services identified in the survey catered for 'all disabled people'. The most common condition specific day opportunities reported were for people with brain injury (37% of PCTs).

Data about access to and coverage of models of care and other services endorsed the findings from our case studies that many people with LTNCs struggle to get a service. Among neuro-therapies, neuro-psychology was particularly scarce with referral systems and waiting lists being problematic; 63 percent of PCTs who reported a service described it as 'difficult' or 'very difficult' to access. The importance of ongoing access to services for people with LTNCs was a recurring theme in our interviews. In the benchmarking survey, only 19 percent of PCTs described their neuro-physiotherapy services as 'ongoing'.

## Implications for policy

Our research suggests that the quality requirements of the NSF for LTNCs were overwhelmed by the competing 'hard' targets PCTs and other organisations had to meet. The NSF for LTNCs came with no new money and no firm targets. As such, there was little to compel organisations, already trying to deal with financial pressures, service restructuring and targets with clear sanctions, to devote much time to achieving the 'softer' quality requirements of this NSF. Nearly half way through the ten-year implementation period, only half of PCTs had a written action plan for implementing the NSF and very few had carried out their plans. Our in-depth case studies found that nurse specialists, CINRTs and certain types of day opportunities are particularly successful in promoting continuity of care for people with LTNCs. However, our benchmarking data confirm that in many PCT areas these services are not available and, even where they are, not everyone with an LTNC has access to them. If statutory service commissioners and providers want to meet the continuity of care requirements encapsulated in the NSF, and needed by people with LTNCs, it is important that all people with an LTNC are able to access one or more of these models close to home, irrespective of where they live or what LTNC they have.

## Methods

This research was funded by the National Institute for Health Research Service Delivery and Organisation programme, and was conducted by SPRU between 2006 and 2010. The research had three main components:

- 1 A rapid systematic literature review of evidence on the impact and costs of integrated models of care for people with LTNCs and what is needed to make these models operate well.
- 2 In-depth case studies of neurology service systems covering six English PCT areas. Case sites covered a range of models of integration in areas with differing demographic characteristics. We conducted in-depth interviews with 151 members of staff in these areas from a variety of statutory and non-statutory organisations, as well as viewing planning documents and observing meetings. We also carried out face-to-face interviews with 71 people with LTNCs covering the full range of condition sub-categories identified in the NSF.
- 3 A survey of all English PCTs to audit progress towards implementation of the NSF nationally and the extent to which integrated services were available to people with LTNCs. We based the audit tool primarily on evidence from the case studies and carried out the survey over the summer of 2009. Questionnaires were completed over the telephone with the identified LTNCs lead or equivalent in each PCT. Of the 152 PCTs in England, 118 responded (78%).

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