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Research Initiative for Long Term Neurological Conditions LTNC

Integrated Services for People with Long-term Neurological Conditions: Evaluation of the Impact of the National Service Framework

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Executive summary

Background

Many people with long-term neurological conditions (LTNCs) require substantial service support, yet the fragmentation of, and lack of access to, social, psychological, specialist and non-specialist support has been evident for over 20 years. The successful management of LTNCs, in order to enhance health and well-being, needs both sophisticated management across a number of health, social care and other service boundaries, and involvement of people with LTNCs and members of their support networks.

The National Service Framework (NSF) for Long-term Neurological Conditions aimed to 'bring about a structured and systematic approach to delivering treatment and care for people with long-term conditions'. The need for an integrated approach to service provision was made clear, explicitly and implicitly, in all of the NSF's 11 Quality Requirements (QRs).

Aims

The current study aimed to:

a) Identify what helps or hinders integrated services and to identify best models and practice of delivering continuity of care from the perspectives of people with LTNCs, their families or informal carers and the professionals who deliver those services.
b) Develop a benchmarking system, based on these models/practice, to assess the initial impact of the NSF for LTNCs on integrated service provision.

Methods

The research had three main components:

1) A rapid systematic literature review of evidence on best models of integrated service provision for LTNCs and how to achieve these models.
2) In-depth case studies in six neurology 'service systems' to identify the key indicators of good quality, integrated service provision and understand its impact on service users and their families or informal carers. Six areas with different approaches to integration were selected. To enable comparisons of similar and different populations and services, the six cases study areas also reflected geographic and demographic diversity.

Tracking and tracing the processes involved in integration is complex. The main *outcome* we might expect from integration is continuity of care. This concept was used as a framework for our case studies. It can be experienced in different ways and we began by using the definitions developed and elaborated by Freeman and colleagues. Qualitative methods, including telephone and face-to-face interviews, non-participant observation and collection and analysis of local literature were used to explore the experience of continuity of care for people with LTNCs.

3) A benchmarking tool to assess the development of integrated services nationally during implementation of the NSF. We triangulated evidence from the literature review and case studies to develop benchmarks which could assess the type, quality and impact of integrated services in local areas. We then designed a questionnaire using the benchmarks and carried out a national survey.

During the case study phase of our research we interviewed a total of 151 staff from a wide range of statutory and non-statutory organisations across the case study sites. We also interviewed 71 people with LTNCs covering the full range of condition subcategories identified in the NSF for LTNCs. The telephone survey methods used in our national benchmarking survey allowed us to contextualise information and achieve a high completion rate (78%). Evidence from the research overall was strengthened by triangulation of different types of data.

Results

The **literature review** found that the evidence base about a) the impact and costs of integrated models of care for people with LTNCs; and b) the service delivery and organisation elements that need to be in place to make these models operate well, was weak. The choice of outcome measures for many of the studies was limited to the conventional, and measures which addressed issues of personal choice, empowerment, or the experience of continuity of care were largely absent. There was some limited evidence that home-based models of integrated care may reduce health service costs and, possibly, those of service users and their families.

Bringing together the views and experiences of staff and people with LTNCs in our **case study sites**, we identified three models of ‘best practice’ for integrated service delivery, each of which contributed to the experience of continuity of care. These were:

1. Nurse specialists

  - This model can promote all forms of continuity of care and is highly valued by people with LTNCs, their families and carers, and other 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 support. With their specialist knowledge and accessibility, they were often people's first port of call, able to answer questions, allay fears and access further support as the need for this arose.

2. **Community interdisciplinary neurological rehabilitation teams (CINRTs)**
   - People in receipt of services from a CINRT (as opposed to lone therapists or 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, but 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 CINRTs a more holistic approach could be taken and cross-sector boundaries became less problematic.

3. **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, valuable member of society.

We also concluded that **care co-ordination** is an element of service provision central to the experience of continuity of care, although this does not constitute a discrete model in itself.

Specialist expertise in LTNCs, or a particular neurological condition, was common to those services valued most by people with LTNCs.

Voluntary sector organisations, particularly those with a focus on specific neurological conditions, were central to the delivery of continuity of care, working hand-in-hand with the above models of service provision.

Timely **access** to valued services, intervention and support was central to the experience of continuity of care. However, it was frequently compromised in a number of ways, including 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.

Results from the **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 Primary Care Trusts (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. 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 problematic and nearly two-thirds of PCTs describing the service as ‘difficult’ or ‘very difficult’ to access. The importance of ongoing access to services for people with LTNCs was a recurring theme in our qualitative interviews. In the benchmarking survey, only 19 percent of PCTs described their neuro-physiotherapy services as ‘ongoing’.

Conclusions

Our research suggests that the NSF for LTNCs, coming with no new money and no firm targets, has been largely overtaken by competing policy, organisational and financial priorities that PCTs and other organisations have had to deal with. Nurse specialists, CINRTs and certain types of day opportunities are particularly successful in promoting continuity of care for people with LTNCs, and yet it is clear that many do not have access to these services. Given the long-term and often progressive or fluctuating nature of neurological conditions, the ongoing nature of these and other services is particularly important.

Future research could usefully focus on:

- Appropriate outcome measures and the cost-effectiveness of the ‘gold-standard’ models of care we identified.
- The impact of the different ways that nurse specialists work.

- The specific experiences of people with LTNCs from different socio-economic and ethnic groups.
- The impact that the failure to access our ‘stronger’ models of care has on both the person with the LTNC and their families and carers.
- An international comparison of how other countries strive to meet the needs of people with LTNCs.