

# **Integrated services for people with long-term neurological conditions**

---

**Gillian Parker, Sylvia Bernard, Fiona Aspinal, Kate Gridley,  
Social Policy Research Unit**

**Kate Light  
Centre for Reviews and Dissemination**



# Acknowledgements

---

- ◆ Project and Programme Advisory Groups
- ◆ SPRU Adults, Older People and Carers Consultation Group
- ◆ Department of Health LTCs Group
- ◆ All participants in the case study areas and all the PCTs that completed the benchmarking tool



# Presentation overview

---

- ◆ Recap on methods
- ◆ Key findings from each stage of the research
- ◆ Key messages

# The project

---

## ◆ Aims

- ◆ To identify best models/practice for integrated services
- ◆ Develop a benchmarking system to assess the initial impact of the National Service Framework for LTNCs on integrated service provision

## ◆ Phases of research

- ◆ Scoping
- ◆ Literature review
- ◆ Case studies
- ◆ Benchmarking

# Scoping

---

## ◆ Methods

- ◆ Contacting SHAs
- ◆ Talking to other key stakeholders

## ◆ Key Findings

- ◆ Low profile of NSF
- ◆ Disruption from re-organisation
- ◆ Summarised in:
  - ◆ Bernard, S., Aspinal, F., Gridley, K. and Parker, G. (2008) Integrated policy making in England for adults with long-term neurological conditions (LTNCs): some preliminary findings from a scoping study, *International Journal of Integrated Care*, vol. 8.



# Literature review

---

- ◆ Discussed at last advisory meeting in detail
- ◆ Key findings
  - ◆ Evidence base is poor
  - ◆ Most research is about ‘conventional outcomes’
  - ◆ What about empowerment, sense of worth, ability to make sense of one’s condition?

# Case studies 1

---

- ◆ In-depth case studies in six neurology service systems to
  - ◆ Identify the key indicators of good quality, integrated service provision from a variety of perspectives
- ◆ Methods and participants
  - ◆ Interviews with staff from health, social, independent services
  - ◆ Interviews with people with a long-term neurological conditions
  - ◆ Observations of key meetings
  - ◆ Reviewing relevant local documents

# Analysis - Continuity of care (Freeman, 2001; 2007)

---

## ◆ Continuity of ...

- ◆ **Management** - Communication and co-ordination across boundaries
- ◆ **Information** - Timely availability of relevant information
- ◆ **Longitudinal** - Minimum number of people needed to provide quality care over time
- ◆ **Long-term** - Provision of uninterrupted care for as long as is needed
- ◆ **Relationship** - Therapeutic relationship over time
- ◆ **Flexible** - Flexibility and adjustment to the needs of the individual over time
- ◆ **Social Context** - Continuation of a person's preferred social and personal situation
- ◆ **Personal Agency** - Continued control over a person's own life and management of their condition



# Management continuity

---

- ◆ Communication between professionals
- ◆ Communication between professionals and people with LTNCs
- ◆ Co-ordination of services within services and sectors
- ◆ Co-ordination of services between sectors

# Example 1: Rose (Site B)

---

Rose had MND and communicated through a lightwriter. She was interviewed with her husband, who told the following story:

*‘After Rose’s chest infection we were actually in this room, and the GP was here, and the OT was here and I think one of the District Nurses or somebody else was here and we were talking about the transition onto the hoist, because Rose was just getting to the stage where she couldn’t really use the turner anymore and I said, “Who is in charge of this case? Who’s overlooking this, who’s got the folder to see how Rose is getting on?”’*

*‘And there’s no real answer to that question. There doesn’t seem to be anybody who sits around worrying about Rose [laughs], apart from me.’*

It was not until the local hospice had become involved and a key worker allocated, that both Rose and her husband felt reassured

# Example 2: Jeremy (Site D)

---

Jeremy was very happy with the organisation of his discharge from an independent sector brain injury rehabilitation centre and his ongoing support.

- ◆ **Social Worker:**

- ◆ The same social worker took responsibility for care co-ordination when he was an inpatient and when he came home
- ◆ Referred to her as 'absolutely fantastic'

- ◆ **Community resource centre** (with specialism in brain injury):

- ◆ Began attending before discharged and continued until found paid employment
- ◆ The centre hosted regular cross sector review meetings

- ◆ **Community brain injury rehabilitation team:**

- ◆ Transferred automatically
- ◆ Directly provide OT and neuropsychology
- ◆ Operate across boundaries, linking with educational provider and his new employer

# Management discontinuity

---

- ◆ Discontinuities occurred when:
  - ◆ No single professional or service had an overall responsibility for a case
  - ◆ There was no-one to pick up the threads when systems broke down
  - ◆ Services/professionals didn't communicate effectively:
    - ◆ Between one another
    - ◆ With people with LTNCs and their families

Again, these link to other forms of continuity ...



# Models that promote continuity

---

- ◆ Community interdisciplinary neurological rehabilitation teams
- ◆ Nurse specialists for neurological conditions
- ◆ Day opportunities  
(Specifically those which offer peer support, social/leisure opportunities and access to meaningful, creative, learning and/or employment opportunities)
- ◆ Other forms of care co-ordination  
(Social workers, community matrons, etc.)

# National benchmarking 1

---

- ◆ Method
  - ◆ Identifying leads at PCT
  - ◆ Developing the benchmarking questionnaire
    - ◆ Triangulating evidence from earlier phases
      - ◆ Models
      - ◆ Issues around access – ongoing, coverage, eligibility
    - ◆ Involving the project advisory group
    - ◆ Cognitive interviewing (7) and pilot (10% - RR – 53%)
  - ◆ Telephone survey of all PCTs in England (152)
    - ◆ Response rate – 90%
    - ◆ Completion – 78%

# National benchmarking 2

---

- ◆ Preliminary results (strategy and organisation)
  - ◆ Joint commissioning arrangements for LTNCs
    - ◆ 12% PCTs fully
    - ◆ 62% PCTs partially
  - ◆ Service users/carers involved in commissioning arrangements – 63% PCTs
  - ◆ Service users/carers involved in service development – 81% PCTs
  - ◆ Cross sector strategic group – 66% PCTs
  - ◆ NSF action plan – 50% PCTs
  - ◆ Care Plan – 5% PCTs >50% people with LTNCs

# National benchmarking 3

---

- ◆ Preliminary results (models)
  - ◆ 73% PCTs had 1 or more CINRTs
  - ◆ 93% had nurse specialists operating in the PCT area
  - ◆ 65% PCTs had a service(s) offering day opportunities
  - ◆ 91% PCTs described services providing care co-ordination
- ◆ Relationships between 'strategy and organisation' and 'models' to be explored

# Key messages

---

## ◆ Models

- ◆ Community interdisciplinary neurological rehabilitation teams
- ◆ Nurse specialists for neurological conditions
- ◆ Day opportunities
- ◆ Other forms of care co-ordination

But it's not just about models or the level of system integration ...

- ◆ Access to and availability of services
- ◆ Specialist expertise/understanding of neurological conditions
- ◆ Recognising the role of the voluntary sector
- ◆ Recognising the role and expertise of people with LTNCs and their families/informal carers in maintaining continuity



# Policy implications

---

- ◆ LTCs agenda impacting on LTNCs
- ◆ Models – nurse specialist funding/day opportunities
- ◆ Personalisation agenda

# Contacts

---

- ◆ Gillian Parker [spru-director@york.ac.uk](mailto:spru-director@york.ac.uk)
- ◆ Sylvia Bernard [smb509@york.ac.uk](mailto:smb509@york.ac.uk)
- ◆ Fiona Aspinal [fa112@york.ac.uk](mailto:fa112@york.ac.uk)
- ◆ Kate Gridley [kg518@york.ac.uk](mailto:kg518@york.ac.uk)

Social Policy Research Unit (SPRU)

University of York

Heslington

York

YO10 5DD