

RI LTNC Newsletter

Edition 2: Spring 2008

Welcome to readers new and old

Welcome to the 2nd edition of the RI LTNC newsletter, with the latest information about 6 studies underway as part of the Policy Research Programme's (PRP) Long Term Neurological Conditions research initiative. In this edition you will find updates from the research teams and news about other developments. If you would like to contribute to future editions please contact me.

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An 'easy read' version of this newsletter can be downloaded from the LTNC web-site (<http://www.ltnc.org.uk/>) and other accessible formats can be produced on request.

New LTNC research: 2008-2010

The Department of Health Policy Research Programme is to commission a supplementary programme of research to inform policy around LTNCs and the tendering process is now underway (the closing date for registration of intention [ROI] was 30th November 2007).

Topics of particular interest include: social and economic inclusion; workforce developments; the incidence and prevalence of rare progressive conditions and user/carer involvement in service development. Further announcements will be made in Spring 2008, following the review process and recommendations made by the Commissioning Group.

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Research Updates

The needs of individuals with progressive neurological conditions and their carers and their experiences of services: a benchmarking study (2006-2009)

Summary by lead researcher Professor Ray Fitzpatrick

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Aims to provide a clear quantitative and qualitative evidence base for the three progressive neurological conditions: Parkinson's Disease (PD), Multiple Sclerosis (MS) and Motor Neurone Disease (MND), including current patterns of health, quality of life, access and experience of services for individuals and their carers.

The main objective of our study is to carry out a survey of health and service experiences of individuals with MND, MS and PD and those of their main carers. The evidence from the survey will form a benchmark to help monitor progress achieved in services following the publication of the National Service Framework (NSF) for LTNCs in 2005.

Firstly, we carried out reviews of evidence about services that are considered appropriate and helpful to individuals with long term conditions. We wanted up to date evidence, taking account of any developments in services since the publication of the NSF. We have also carried out in-depth interviews with individuals with MND, MS or Parkinson's and with a sample of carers, in order to help us see services from the perspective of users.

We invited a group of individuals (with an LTNC) and carers to form a Research Advisory Group. We are now about to pilot the survey via a number of regional branches of charities.

Integrated services for people with long-term neurological conditions: an evaluation of the National Service Framework. (2006-2009)

Lead researcher – Professor Gillian Parker
Summary by Dr Sylvia Bernard

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This project aims to identify the factors that help or hinder the development of integrated services for people with LTNCs. Once identified, a 'benchmarking' system will be designed, based on these factors. This will then be used to assess whether the NSF for LTNC has had an impact on the integration of services.

Interviews with people with LTNCs, their organisations, informal carers and health and social care professionals have informed our understanding of the factors which appear to help or hinder the process of integration. They have also helped us identify six geographical areas which will act as case studies for the next stage of the project.

The second element of the scoping phase, the systematic literature review, is ongoing and a draft publication reporting some of the preliminary findings from the scoping work has been prepared. It is hoped to disseminate this early in 2008.

Six Primary Care Trust areas have been recruited for in-depth case studies of their neurology 'service systems' and interviews in these areas will be the main focus over the coming months. The results will be placed alongside findings from stage one to strengthen the development of key indicators of good practice and develop 'benchmarks'. We are also working in partnership with a group of neurological charities to develop the audit tool 'Quality Neurology'. (See: "Quality Neurology", page 6)

Support for carers, particularly those with multiple caring roles: an investigation of support needs and the cost of provision (late 2006-2009)

Lead researcher: Professor Lynne Turner Stokes
Summary by Dr Diana Jackson

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Aims to increase understanding of the problems faced by people who care for someone with a LTNC, and learn from their experiences what kinds of support helped, or what would have helped if it had been offered.

The development phase is now complete and a final version of the questionnaire schedule and follow-up telephone interview guide has been agreed. This was informed by:

- Several rounds of feedback from members of our Project Advisory Panel (comprising six carers and representatives from four voluntary organisations);
- Responses from fifteen carers who completed questionnaires and interviews as part of the pilot study.

Information about the study is being widely disseminated. Six national voluntary organisations have posted details with on-line reply forms on their websites, and are mailing details to members in routine newsletters. Recruitment of carers from black and minority ethnic communities is also being pursued.

Research approval has been given to recruit carers via three neuroscience centres, and is awaited for a further six. Questionnaires are now being sent out and returned. Data management procedures are in place. A database with validation rules has been set up and tested.

Regular contact continues with the project team researching palliative care needs (see *Tariq Saleem's summary, page 6*). Pooled analyses will be carried out on some carer data across the two studies.

Long-term Involvement in Fitness Enablement (LIFE) study (mid 2006-2009)

Summary by lead researcher Dr Helen Dawes
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This study aims to establish how people would like exercise programmes supported; to provide information on community facilities for maintaining mobility and to determine whether exercise delivered in a leisure centre, with a physical activity provision support system, is effective in improving activity levels.

The LIFE project is using a range of different research methods to develop a Physical Activity Support System (PASS) that will help people with long-term neurological conditions to keep fit by using Inclusive Fitness Initiative (IFI) centres. We have completed early focus group work and pilot feasibility investigations to guide our development of a person-centred support system and a fitness professional support system for use within IFI centres. A randomised controlled trial examining levels of participation and adherence at IFI centres, when supported with the developed PASS, is now underway.

Studies examining the extent to which people with neurological conditions use community fitness centres to keep fit are continuing.

Transition to adulthood: the experiences and needs of young men with Duchenne Muscular Dystrophy (DMD), and their families (late 2006-2009)

Lead researcher - Professor John Carpenter

Summary by David Abbott

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This study aims to find out how:

- The health and well-being of young men living with DMD and their carers can be maximised, particularly during transition to adulthood;
- The NSF for LTNC can help service developments for this group of service users;
- Practically based theories can help us understand the relationships between people with LTNCs, their carers and services; and
- What lessons can be learnt from this research for young adults with other LTNCs.

Our first young people's reference group was held at the Cheshire Neuro-Muscular Centre in July. Pilot interviews with 3 families which included siblings helped us to fine-tune the topic guide.

The study was given Multi-centre Research Ethics Committee (MREC) approval in August and the survey is underway. Interviews in 3 areas are ongoing and 24 families have already taken part, involving a range of family members.

The research team network at relevant national and international events.

Links have been made with Action Duchenne, and their researcher, who is doing work on access to clinical trials. Also, contact has been made with researchers at the Erasmus University Medical Centre, Rotterdam who have a programme of work around transition. A study visit is taking place in January 2008 to find out more about each other's work.

Defining the palliative care needs of people with late stage Parkinson's Disease (PD), Multiple System Atrophy (MSA) and Progressive Supranuclear Palsy (PSP) (late 2006-2009)

Lead researcher: Professor Nigel Leigh

Summary by Tariq Saleem

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This research aims to gain better understanding of the experiences and needs of people severely affected by PD, MSA and PSP in order to identify the most effective approaches to enhancing quality of life and providing personalised support and resources for families living with these conditions.

I was appointed to work on this project in June 2007. The research programme consists of two complementary parts.

Currently, we have successfully identified participants with help from the Movement Disorder Team at King's College Hospital. Interviews are taking place throughout the South East of England. Participants are being followed up at 4-monthly intervals. An advisory group, comprising those with personal experience of these conditions, or representing the relevant support Charities, is meeting in early 2008 to discuss the emerging data and give their views on developing the qualitative interview phase.

We maintain close liaison with the Support for Carers study (see page 3) and we have had meetings to explore ways of combining analysis from the two studies. Overall, progress has been excellent with enthusiastic and committed participation from those experiencing these conditions. Further details of the study can be found on our webpage: <http://www.kcl.ac.uk/palliative>.

A study to look at the needs of young people when they require adult services: new findings from Personal Social Services Research Unit, London School of Economics (PSSRU, LSE)

Health and social care needs of young people with long-term neurological conditions on transition to adult services and the costs of service provision

Margaret Perkins - email: M.A.Perkins@lse.ac.uk

Summary

PSSRU was asked by the Department of Health (DH) to look at the experiences of young people who require adult services. The focus of this short piece of work was to look at services used by people aged 18-25 with neurological conditions and to investigate the costs involved that enable young adults with neurological conditions to live independently. The project was linked to the RI LTNC.

It has been estimated that 10 million people in the UK have a neurological condition, over 8 million of whom require practical support. Getting the right support is seen as crucial to achieving independence and maximising opportunities and is an important policy concern.

Three neurological conditions were selected because of their relatively high prevalence, and because they encompass a range of impairments and experiences found among the young people concerned:

- Epilepsy is an intermittent condition where specialist services are needed during acute episodes or to respond to changing needs;
- Cerebral palsy (CP) is an early onset condition;
- Acquired brain injury (ABI) is a sudden onset disorder, often affecting people in this age group.

We sought to identify the health and social care support and services currently used by young adults with each of these conditions, along with the costs and the unmet needs for health and social care.

Overview of findings

The picture that emerges is that:

- There is widespread under-recognition of needs and poor support during the transition to adult services;
- Discontinuities in service contact are common;
- Social care support is frequently reported as low;
- Many young adults remain heavily dependent on their parents;
- Opportunities for independence are severely restricted.

Shortages of specialist services and staff and specialist training for generic staff are partly to blame. Two other areas of unmet need were striking; day time activities and information.

The data suggest that a quarter of young adults with epilepsy are permanently unable to work and one in five young adults with CP stay at home with no formal day time activity. Many young adults with epilepsy or CP had entered further education courses but the high unemployment rates suggest that attendance does not always improve access to work. Community-based day activities for young adults with ABI also appear to be in short supply.

Young adults and their carers were concerned about the lack of information about their condition, its implications for other areas of the young adults' lives and the services that were available. For agencies, poor information about the numbers of young adults in their area and their health and social care needs leads to difficulties in planning, commissioning and providing appropriate levels of support.

A summary of the research findings will be available on the LTNC website (www.ltnc.org.uk/research.htm) in early 2008.

Other News

Costs, quality and outcomes of community equipment services (2007-08)

Lead researcher – Professor Ann Netton

Summary by Nick Smith

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The principal objectives of this research are to:

- Identify methods of measuring equipment service outputs, quality and outcomes for disabled adults;
- Identify the use of equipment and adaptations over time;
- Provide an understanding of the costs of community equipment services and the relationship between cost, quality and outcomes;
- Investigate factors underlying variations in efficiency of community equipment services.

Over 4 million people use equipment provided by health and social care services. However, there is a lack of tools with which to measure both the quality of the service they receive and the impact equipment makes on people's lives. The PSSRU has been developing measurement tools for the forthcoming DH User Experience Survey of people receiving community equipment and minor adaptations funded by Social Services. In addition to the required local authority survey, the PSSRU has invited local authorities to take part in an extension study which aims to:

- Add value to the survey by enhancing comparability between authorities across dimensions not included in the required items;
- Assess the questions for their suitability as performance indicators;
- Facilitate the further development of a measure of quality and outcomes of community equipment services;
- Enable authorities to compare the quality of the community equipment service in their authorities with other authorities.

The survey will be carried out in early 2008. A report detailing the development of the PSSRU's measures will be available on our website (www.pssru.ac.uk) in Spring 2008.

Quality Neurology (April 2007- 2009)

Contact: Sheila Lakey, Project Manager, MS Society: slakey@mssociety.org.uk

The MS Society, Parkinson's Disease Society (PDS), Motor Neurone Disease (MND) Association and Ataxia UK are collaborating to develop a 'person-focussed' audit tool, based on the NSF for LTNCs. Quality Neurology is funded by the partners and a grant from DH (PRP). It will be evaluated by the Social Policy Research Unit at York University (see Sylvia's report page 2).

The aim is to provide a framework for Health and Social care services to assess their progress against the 11 Quality Requirements of the NSF for LTNCs in order to make improvements.

The audit tool will be developed by measuring organisational progress against the NSF in up to 10 selected areas, with service users and carers being at the centre of the assessment process.

Report on Research into Assistive Technology

Foundation for Assistive Technology (FAST)

The 2006-2007 edition of the Annual Parliamentary Report on Assistive Technology (AT) Research and Development was presented to Parliament in July 2007 and is freely available to download from FAST (<http://fastuk.org/home.php>) This is the 6th report that FAST has produced for DH and the information in it is drawn from its national database of AT research and development. It is designed to reflect the work funded (directly or indirectly) by the UK government, but FAST's database incorporates work funded from a wider range of sources.

Publication News

Modernising Adult Social Care: what's working

Published June 2007

The report draws on 9 research projects and 2 baseline studies commissioned and conducted between 2003 and 2007, as well as emerging themes from other DH commissioned research. The report presents the findings from each study and gives an overarching assessment of the Modernising Adult Social Care programme as a whole. It is available from:

www.masc.bham.ac.uk or

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_076203

Mapping the capacity and potential for User-Led Organisations in England

Published September 2007

This research report presents the main findings of a national research study to obtain up to date information about local User-led Organisations and Centres for Independent or Integrated Living in England. It was commissioned by the Department of Health as part of its commitment to lead on delivering recommendation 4.3 of "Improving the Life Chances of Disabled People", a Prime Minister's Strategy Unit report. This report recognises that local organisations, run and controlled by disabled people, will be a vital part of the implementation of a new approach to supporting independent living.

Available from:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_078538

Valuing People and Research: The Learning Disability Research Initiative

Published November 2007

The report is the culmination of 13 studies conducted between 2001 and 2007. It assesses the impact of the Learning Disability Research Initiative (LDRI) on policy and practice, particularly in relation to the inclusive research agenda. It provides evidence of the extent to which the "choice and personalisation" policy agenda is being implemented locally and the gaps and challenges that now need to be addressed.

The full document and an easy read version can be downloaded from www.ltnc.org.uk.

News from the Advisory Group

About the group

The Advisory Group was established at the start of the initiative to provide advice and guidance on setting up and monitoring this initiative. Members bring specialist knowledge and expertise to help with making decisions about the priorities for the programme. The group meets twice a year. It receives, and comments on, progress reports and research documents as they are produced. A smaller sub-group oversees the commissioning and tendering process.

Tribute to Roy Webb

Just as our last newsletter went to print Roy Webb, an Advisory Group member, died suddenly. Roy will be warmly remembered, as well as sadly missed by all who knew and worked with him. In the words of one of the group, he will be remembered as "a champion of self-determination for disabled people".

Changes to the group

Other members are moving on due to changing circumstances. We are sorry to say goodbye to: **Andrew Nocon, Professor Sally Byng, Liz Housden, Barrie Fiedler, Paul Kyprianou** and **Patience Wilson**, but we are pleased to welcome:

Lucy Brazg is Policy and Development Manager of the Neurological Alliance. Previously she has worked for the World Health Organisation, focussing on the development of sanitation and safe hygiene practices in schools. For many years Lucy was a trustee of a local charity delivering services for older people.

Dr Kate Swinburn works for Connect which is a voluntary organisation that works to promote practical, creative and lasting ways of living with communication disability after stroke. Kate is a speech and language therapist with clinical and research experience who now works exclusively in the voluntary sector.

Dr Ghazala Mir is a Senior Research Fellow and Director of the Ethnicity Training Network at the Centre for Health and Social Care, University of Leeds. Ghazala's research interests include health inequalities affecting people with learning disabilities and people from minority ethnic communities. She is also involved in studies relating to faith identity and social exclusion.

David Ellis works for the Social Care Institute for Excellence (SCIE), where he advises on making SCIE's work relevant to service providers, people who use services, commissioners and policy makers. He is also the theme leader for Effective Services for Adults.

Gillian Ayling replaces Patience Wilson as Department of Health's representative from within the Social Care Directorate.

The LTNC Advisory Group



Back row from left to right: Richard Parnell, Kate Radford, Cath Sackley, Conrad Hodgkinson, John Holt, David Ellis.
Middle row from left to right: Anne Chamberlain, Carol Lupton, Maggie Winchcombe, Farheen Shafiq, Julia Johnson, Kate Swinburn.
Front row from left to right: Bev Hopcutt, Barrie Fiedler, Christine Barton, Gillian Chedzoy, Sandra Paget.