



## Research Initiative for Long Term Neurological Conditions

# A new research initiative to support implementation of the National Service Framework

### Introduction by Maggie Winchcombe, Scientific Adviser

The National Service Framework for Long Term Neurological Conditions (NSF for LTNC) sets out Quality Requirements for health and social care services that will lead to improved provision for people living with long term neurological conditions.

The Research Initiative for Long Term Neurological Conditions (RILTNC) has now been established by the Department to assist its implementation. Key objectives in commissioning the research were to:

- obtain baseline data so that progress can be measured over time;

- gather evidence that would be transferable across services and communities;
- encourage research that demonstrated a 'whole system' approach and strong partnerships between academic, user and practitioner communities.

Six studies have been commissioned and the initiative will run for three years, after which a final report will be published drawing on all the findings from the research.

The initiative is supported by an Advisory Group with a wide range of experience, expertise and interests in living with,



and researching, long term neurological conditions. In this first edition of the LTNC Newsletter we introduce them to you, along with other team members and information about the six studies.

### **Want to keep informed? Visit the LTNC Website!**

This newsletter complements the LTNC website in providing news and information about the initiative. The website aims to give up-to-date information about the research and the people behind it, as well as provide an opportunity for practitioners and service users to comment and help to disseminate the information. It will be regularly revised as news is received from the research teams. Links to other sites and items of interest will be included as appropriate.

The website can be found at [www.ltn.org.uk](http://www.ltn.org.uk)



## The LTNC Project Newsletter

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### Published by

The Research Initiative for Long Term Neurological Conditions Project Team.

Electronic copies of this newsletter are available at [www.ltnc.org.uk](http://www.ltnc.org.uk)

Commissioned and funded by the Department of Health through its Policy Research Programme.

The views expressed in this publication are not necessarily those of the Department.

### Alternative Formats

This newsletter can be downloaded as a screen-readable PDF document from [www.ltnc.org.uk](http://www.ltnc.org.uk), and is also available on cassette or disk.

Please contact [maggie@ltnc.org](mailto:maggie@ltnc.org) for more information.

# About the research studies

The Department invited research proposals from a range of disciplinary perspectives. A Commissioning Sub-Group, drawn from the Advisory Group, supported the Department's selection process. A large number of outline applications were received and 26 applicants were invited to submit full proposals. After a rigorous review process, which involved academics, service users and carers and practitioners, the following studies have been recommended and accepted for funding.

### **Integrated services for people with long-term neurological conditions (LTNC): an evaluation of the impact of the National Service Framework**

The lead researcher for this project is Professor Gillian Parker of the University of York. Work started during 2006 and the research team was in place by the end of the year.

The aim of the research is to identify the factors that help or hinder the development of integrated services for people with LTNCs. Once identified, a 'benchmarking'\* system, based on these factors, will be designed. This will then be used to assess whether the National Service Framework for LTNC has had an impact on the integration of services.

\* 'Benchmarking' is a way of making comparisons between services in order to identify the best way of doing something; it is seen as an effective way of improving public services.

Contact: Professor Gillian Parker

[gmp501@york.ac.uk](mailto:gmp501@york.ac.uk)

### **The needs and experiences of services by individuals with progressive neurological conditions, and their carers: a benchmarking study**

This project started at the end of 2006 and is being led by Professor Ray Fitzpatrick, Division of Public Health and Primary Healthcare, University of Oxford.

This study will provide clear quantitative and qualitative evidence to give us a 'benchmark' of evidence against which progress in implementing the NSF's Quality Requirements can be measured. It will also identify specific areas of service requiring particular attention.

The survey instrument will also be a robust tool for use in monitoring progress.

Contact: Professor Ray Fitzpatrick

[raymond.fitzpatrick@nuffield.ox.ac.uk](mailto:raymond.fitzpatrick@nuffield.ox.ac.uk)

### **Transition to adulthood: the experiences and needs of young men with Duchenne Muscular Dystrophy (DMD) and their families**

With modern improvements in healthcare young men with DMD should be looking forward to living independently with appropriate support from public services. However, according to members of the Duchenne Family Support Group this is not happening.

Professors John Carpenter (University of Bristol) and Kate Bushby (University of Newcastle) are co-leading this study to investigate how:

1. The health and well-being of young men living with DMD, and their carers, can be maximised
2. The NSF will help with the development of appropriate services
3. Practically based theories can help us to understand the relationships between people with LTNCs, their carers and services
4. Lessons from this research can be applied to young people with other LTNCs.

The Research team is now in place and work is underway.

Contact: Professor John Carpenter

[j.s.w.carpenter@bristol.ac.uk](mailto:j.s.w.carpenter@bristol.ac.uk)

### **Long-term involvement in fitness enablement (LIFE) study**

Rehabilitation for people with LTNCs in the UK is mainly delivered in hospitals by physiotherapists, using a medical model. This approach does not empower people to become involved in community-based activities, although it is known that regular leisure-time activities provide many other health and social benefits.

Dr Helen Dawes, of Oxford Brookes University, is leading this study which aims to:

1. Establish how people with LTNCs would like exercise programmes supported
2. Provide information on current community mobility
3. Determine whether exercise delivered in a leisure centre which provides a physical activity support system is effective in improving activity levels.

The project started in January 2007. Information obtained from this study will be used to inform a bigger national study.

Contact: Dr Helen Dawes

[hdawes@brookes.ac.uk](mailto:hdawes@brookes.ac.uk)

### **Defining the palliative care needs of people with late stage Parkinson's Disease, Multiple System Atrophy (MSA) or Progressive Supranuclear Palsy (PSP)**

This study is being led by Professor Nigel Leigh, Institute of Psychiatry, Kings College, London.

Parkinson's Disease (PD), Multiple System Atrophy (MSA) and Progressive Supranuclear Palsy (PSP) are severe and progressive neurological disorders of middle and late life but there is no robust evidence on the palliative needs of people with these conditions.

The Study sets out to understand the experiences and needs of people severely affected by these conditions in order to identify the most effective approaches to enhancing their quality of life and providing flexible, personalised end of life support. This will inform future provision through health and social services, the voluntary sector (user groups, support groups and providers) and help from their families and friends.

Work started in early 2007.

Contact: Professor Nigel Leigh  
[n.leigh@iop.kcl.ac.uk](mailto:n.leigh@iop.kcl.ac.uk)

### **Support for carers, particularly those with multiple caring roles: an investigation of support needs and cost of provision**

This study builds on the extensive work already undertaken by lead researcher Professor Lynn Turner-Stokes, of Kings College London.

The research aims to increase our understanding of what support is needed by people who care for someone with a LTNC, particularly when that person has 'multiple caring roles' – that is, they are also the main, or sole, carer for children, an ageing parent or another family member.

The project outputs will inform recommendations, or guidelines, to help professionals to offer the most appropriate types of support. An economic analysis will provide information about the likely cost of providing different types of support.

Contact: Please contact Dr Diana Jackson for further information about the research.

[email: diana.m.jackson@kcl.ac.uk](mailto:diana.m.jackson@kcl.ac.uk)

# The team...

The programme is managed and overseen by a small team, led by the Department of Health and supported by an Advisory Group, who contribute their time on a voluntary basis.

## **Dr Carol Lupton** Policy Research Programme, the Department of Health

Carol is currently working in the Policy Research Programme (PRP) at the Department of Health (DH). Within the PRP, Carol is responsible for commissioning research on ageing and older people, long-term conditions and social care for adults as well as for two DH-funded research units: the Personal Social Services Research Unit and the Social Policy Research Unit. Before joining DH, Carol was Director of an applied policy research unit, where she worked on a range of studies in the health and social care field. Her main research interest is in the development of innovative social science designs for understanding complex real world situations.

## **Maggie Winchcombe, O.B.E., F.C.O.T** Scientific Adviser

Maggie's role as Scientific Adviser is to liaise between the Department of Health and the research communities involved in the programme and to disseminate the results of their research to the practitioner and service user groups who need to know about it.

Maggie qualified as an occupational therapist in the early 1970s and from 1983 worked in the voluntary

sector, specialising in disability equipment information and advice; first locally, and then at regional and national levels. She has published a number of articles, reports and good practice guides relating to the disability equipment field.

In 2003 she left the voluntary sector to work independently. She became a Fellow of The College of Occupational Therapists in January 2006 and was awarded an OBE in the New Year's Honours List, 2007.

## **Anthony Travis** Communications

Anthony is a freelance voluntary sector consultant with a special interest in Communications. He has over 25 years of experience in the voluntary, statutory and private sectors. He has worked in and for transport, disability, health and arts organisations. He has also served on management committees of both local and national organisations.

Anthony has designed printed and electronic communications materials for voluntary, statutory and private organisations at local and national level.

He has developed, implemented and managed a range of projects, and developed major grant applications for, local and national organisations.

## **Sophie Lederer** Administration

Sophie worked for seven years, as Unit Administrator, in the Social Services Research and Information Unit at the University of Portsmouth. During this time she also studied for a degree on the University's Partnership Programme and, having graduated with a BA Honours in Typographic Design in 1996, left the University to pursue an alternative career in the world of design.

Having worked for a design agency and then an event marketing company, Sophie took time out to be a full-time mother to her two children. After a near seven year break, broken only by a brief stint of part-time teaching in Adult Education, Sophie is making a return to work on a part-time basis with this post.

## ...and the Advisory Group (in alphabetical order)

### **Christine Barton MBE**

Service User

Christine has worked in the education field and is firmly committed to enabling disadvantaged people to achieve their rights and improve their quality of life.

Christine has multiple sclerosis and therefore personal experience of receiving social care.

### **Professor Sally Byng, OBE**

Chief Executive, Connect

Connect is a national voluntary organisation that works to promote practical, creative and lasting ways of living with communication disability after a stroke.

### **Professor M Anne**

**Chamberlain, OBE**

Emeritus Professor of Rehabilitation Medicine, Leeds University

Anne has led research on practical rehabilitation problems, and continues to be part of the research unit. She is President of The European Academy of Rehabilitation Medicine

### **Gillian Chedzoy**

Service User

Gillian was diagnosed with multiple sclerosis about 18 years ago. As a Citizens Advice Bureau volunteer she has had the opportunity to observe the effects of disability across a range of issues, particularly financial ones.

### **Barrie Fiedler**

Social Care Consultant

Barrie undertakes policy analysis, service evaluation, research and writing, mainly on the needs of and services for disabled people.

### **Conrad Hodgkinson**

Carer

In addition to his role as a carer, Conrad works as a freelance journalist specialising in disability issues. He is a member of the management committee of Sheffield Carers Centre.

### **John Holt**

Carer

John is secretary of both Newbury & District Branch of the MS Society, and of West Berkshire Neurological Alliance. He is involved in a broad range of activities that will lead to improvements in health and social care provision.

### **Beverley Hopcutt**

Speech & Language Therapist

Beverley is seconded to the Department of Health as Clinical Advisor on the National Service Framework for Long Term Neurological Conditions

### **Representative of the Neurological Alliance**

To be confirmed

### **Julia Johnson**

Speech and Language Therapist

Julia represents the Royal College of Speech and Language Therapists (RCSLT) as part of her duties as a regional clinical adviser for adult neuro-degenerative disorders.

### **Jeff Jerome**

Director of Social Services and Housing – London Borough of Richmond upon Thames

Jeff is joint Chair of the Association of Directors of Adult Social Services Disabilities Committee.

### **Paul Kyprianou**

Director, Icarus Icon Ltd

Paul was Community Care Development Manager for Liverpool City Council's Social Services Department. A qualified social worker, he has extensive experience of evaluation & research.

**Dr Andrew Nocon****Senior Research Officer, Disability Rights Commission**

Andrew is responsible for research commissioning and management in the Disability Rights Commission (DRC) in relation to employment, health and independent living.

**Sandra Paget****Service User**

Sandra has had a rare neurological condition since early childhood. She was an elected member of the Executive Committee of The Neurological Alliance, representing Regional Neurological Alliances.

**Richard Parnell, MSc FRSM****Scope**

Richard is Head of Research at Scope, the national disability organisation with a focus on cerebral palsy. He has an academic background in social science and has worked in the area of social research for many years.

**Dr Kate Radford****Occupational Therapist**

Kate is Honorary Research Fellow (Occupational Therapist) at the Ageing and Disability Research Unit, University of Nottingham. She combines part time research with clinical work as a neurology Occupational Therapist.

**Professor Cath Sackley****Physiotherapist**

Cath holds the Chair of Physiotherapy Research at the University of Birmingham's School of Health Science. Her research work arose from her clinical experience and is focused on community rehabilitation.

**Maria Strudwick****Department of Work and Pensions**

Maria's work involves commissioning research companies to undertake evaluations of Government policy including programmes to help disabled people, such as New Deal for Disabled People.

**Professor Alan Thompson****Consultant Neurologist**

Alan holds both an academic role and a clinical one at University College London and University College London Hospitals. He is also a national adviser to the MS Society and Vice Chairman of Multiple Sclerosis International Federation Medical Advisory Board.

**Roy Webb**

Policy Officer, National Centre for Independent Living (NCIL)

Roy has worked in the disabled people's movement for many years, and has wide experience in the voluntary sector and in the trade union and Labour movement. He has worked for National Centre for Independent Living (NCIL) for nearly four years, in a role which supports and develops organisations and structures which will enable disabled people to live more independently in the community.

**Patience Wilson****The Department of Health**

Patience is the Programme Head for the Long Term Conditions National Service Framework within the Department of Health's Social Care Directorate.

# Advisory Group - Terms of Reference

The Advisory Group was established at the start of the initiative to provide advice and guidance on setting up and monitoring this programme of research.

The broad aims of the research programme are to:

- establish effective systems to identify and measure need for services for people with long term neurological conditions
- understand the implications for the health and social care workforces in meeting that need
- establish a robust evidence base to support future service development
- establish effective mechanisms for evaluating progress and measuring the impact of the NSF.

The Group brings specialist knowledge and expertise to assist in making decisions about the key priorities for the research programme within these aims.

A sub-group, drawn from the Advisory Group, oversees the commissioning and tendering process for the programme.

The group receives and comments on progress reports from individual studies within the programme.

The Group advises on dissemination of key messages from the research as they are identified, so that they reach as wide an audience as possible for maximum impact.

The Group meets at least twice a year for the duration of the initiative and comments on research documents as they are produced.



**Advisory Group members:  
November 2006 meeting**  
Front row: from left to right

Maggie Winchcombe, Gillian Chedzoy, Richard Parnell, Carol Lupton, Barrie Fiedler, Sandra Paget

**Back row: from left to right**

Kate Radford, John Holt, Patience Wilson, Christine Barton (on screen via video link), Conrad Hodgkinson, Andrew Nocon, Julia Johnson