

RI LTNC Newsletter

Edition 4: Summer 2009

Editor's foreword

by **Maggie Winchcombe**, Adviser, RI LTNC
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Welcome to our summer edition of the RI LTNC newsletter with the latest news about research to support the National Service Framework (NSF) for Long Term Neurological Conditions (LTNC). There are now eleven studies underway as part of this initiative and we feature two of them in this issue. On the next page you can read about the latest study to start and on page 4 there is a preview of the findings from the first study to be completed. You can also catch up with news on the publications front and changes to the Advisory Group.

The LTNC newsletter complements our dedicated website, www.ltnc.org.uk, with the aim of spreading the word as widely as possible about this initiative from the Department of Health's Policy Research Programme. An 'easy-read' version of this newsletter can be downloaded from <http://www.ltnc.org.uk>, and other accessible formats can be produced on request. I hope you find it interesting. Please let us know what you think!

Contents

- 2 New Study - Vocational Rehabilitation Services
- 3 Publication News
Initials and Abbreviations
- 4 LTNC focus: Growing up with Duchenne Muscular Dystrophy
- 6 RI LTNC Studies
- 8 Advisory Group News

New LTNC research

New study focuses on Vocational Rehabilitation

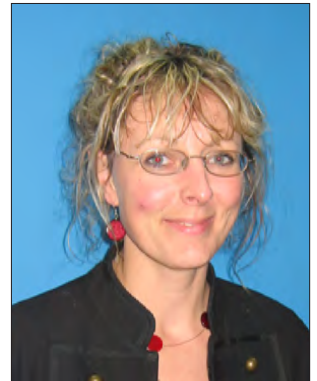
There are 6.8 million disabled people of working age in Britain, but only 51% of them are in work. There is now a great deal of evidence that work can improve the quality of people's lives in a number of ways (not least the benefits of a regular wage).

As a result, services are being set up to help disabled people to stay in their jobs or return to work after ill-health. These new services, known as vocational rehabilitation (VR), can be part of the NHS, or linked to Job Centre Plus, or provided by voluntary and private organisations.

Despite these developments, there are concerns that these services do not meet the differing needs of people with neurological conditions, which may be unpredictable, or intermittent, or constantly changing. This means that people with LTNC are often excluded from this type of support. New guidelines recommend that organisations work together to bridge any gaps and ensure that people can use their services as and when they require them. However, as yet, there is no clear picture of the extent to which these guidelines are being followed. Nor is it known whether they are making a difference for people with LTNC. This study will investigate this in order to produce:

- a directory of specialist VR services that cater for people with LTNC;
- maps showing the location of specialist VR services in England;
- a questionnaire that can be used again to monitor the development of new VR services;
- an online forum for sharing information about services, which will include examples of good VR services.

The study started in February 2009. It is being led by Drs Kate Radford (pictured right) and Diane Playford.



Diane (pictured below) tells us that it has "got off to a flying start".



A new researcher, Ali Gibson, has been recruited, the necessary ethics approvals have been obtained and the steering group and expert panel have met. Progress is now being made in getting the survey underway.

For more information please go to our website: www.ltnc.org.uk/research_files/mapping_vocational_rehab.html

Publications News

Research and development work relating to Assistive Technology

Foundation for Assistive Technology (FAST)

The 2008-2009 edition of the Annual Parliamentary Report on Assistive Technology Research and Development was presented to Parliament in July 2009 and is freely available to download from FAST (<http://fastuk.org/home.php>). This is the 8th report that FAST has produced for the Department of Health describing the work funded (directly or indirectly) by the UK government. It draws on FAST's national database of assistive technology (AT) research and development in the UK which is a comprehensive and up-to-date resource for anyone with an interest in this field.

Patient and public involvement in research and research ethics committee review

National Research Ethics Service & INVOLVE

The National Research Ethics Service (NRES) and INVOLVE (a national group that supports and promotes active public involvement in research) have published a joint statement to provide clarity and guidance for ethics committees on patient and public involvement in research. It has been approved by the NRES Advisory Group and the NHS Service Users and Ethical Review and can be downloaded here: http://www.invo.org.uk/pdfs/INVOLVE_NRESfinalStatement310309.pdf

Glossary of initials

Initial or abbreviation	Explanation
ACPIN	Association of Chartered Physiotherapists in Neurology
ADASS	Association of Directors of Adult Social Services
AT	Assistive Technology (defined as any product or service designed to enable independent living for disabled and older people).
DDA	Disability Discrimination Act
FAST	Foundation for Assistive Technology
LTNC	Long Term Neurological Conditions
NRES	National Research Ethics Service
NSF	National Service Framework
PCT	Primary Care Trust
QR	Quality Requirements (set out in the National Service Framework)
VR	Vocational Rehabilitation (VR means providing training and support in developing skills or learning a new trade with the aim of getting a job)

LTNC focus

The final report from a study that looked into the experiences of young men with DMD and their families

Duchenne Muscular Dystrophy (DMD) is an inherited neuro-muscular condition that affects boys. Medical improvements mean that boys with DMD are now living longer than ever before and face a particular set of challenges as they reach adulthood.

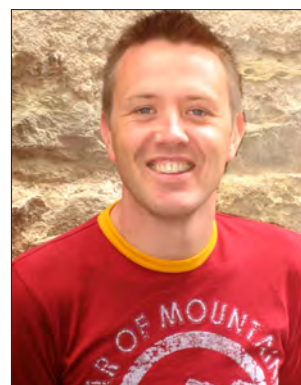
Those who were the focus of this study, aged 15 years and over, had reached (or were reaching) adulthood, a situation that was largely not anticipated when they were first diagnosed. Generally, not much thought had been given (outside their individual families) to what they should do with their lives, or what services they might need. Given their increased life expectancy, young people with DMD should be looking forward to living independently, with appropriate support, as adults.

The study was carried out in three regions in England, the South West, the West Midlands and the North East, between January 2007 and December 2008. It had two main stages:

1. A postal survey of parents with a son with DMD aged 15+.
2. Face to face interviews with 40 families, primarily to seek the views of young men living with DMD (as well as their parents and siblings) about their experiences of growing older with DMD and the issues they face as they become adults.

Maggie Winchcombe: What were your main aims for the study?

David Abbott: (pictured right) We wanted to find out how the health and well-being of young men with DMD, and that of their carers, could be maximised, particularly as they reached adulthood. We were keen to learn from their experience so that we could better understand what's important for young people with long-term conditions and their carers. We also wanted to see how the NSF for LTNC had influenced services for this group of people and to see if there were lessons for others with neurological conditions.



MW: We all tend to take our social lives for granted. What was the experience of the young men in your study?

DA: Those young men who were still in full-time education tended to feel that their social lives were alright. However, those who weren't, especially if they were at home during the day, sometimes had very limited social opportunities, or friendships beyond their immediate family. It was hard for young men to become independent when they relied so much on their parents for transport and support. Few families (and none of the young men themselves) used Direct Payments to buy personal assistant time to support their son's leisure activities.

Growing up with Duchenne Muscular Dystrophy (DMD)

is now being prepared. Maggie Winchcombe talks to researcher David Abbott about the work.

MW: Have the changes brought about by the Disability Discrimination Act (DDA) had an impact on these young people's lives?

DA: The young men in our study were often adversely affected by society's disabling barriers such as physical access, discriminatory attitudes and some services which did not meet their needs. In addition, the physiological affects of DMD restricted their choices about how they spent their time and the opportunities they had for increasing their autonomy and independence. For example, pain was frequently mentioned as a source of distress and major health interventions, such as spinal surgery, could dramatically affect young people's lives.

MW: What evidence, if any, did you find that services were providing the kind of support that young men and their families need?

DA: The main findings confirm that service provision is generally problematic. It was common for families to describe how they had to prove their sons' needs over and over again. They felt this often involved 'fights' and 'battles' and the onus was on them to 'sort things out.' Young men with DMD were often aware of these disputes and found them upsetting and stressful. When families did have positive experiences it was because of factors such as good co-ordination (because they had access to a muscle clinic), planning ahead, and long-standing relationships between the family, the young man, and helpful professionals.

MW: How will the study contribute to service developments for other people with LTNC?

DA: The resulting data gives us deep insights into the reality of daily life for the individuals concerned and their families. It will help to identify, prioritise and develop new kinds of support services for the future. Many improvements can be made quite simply through better co-ordination, information and change of attitudes, all of which are routinely required as part of quality services.

For further information about this study and to download the final report on publication (late summer 2009) please go to: www.ltnc.org.uk/research_files/Transition_to_adulthood.html

RI LTNC Studies

The nine other studies in the initiative are progressing well. For more details of each project and the latest research reports, go to the LTNC website - www.ltnc.org.uk

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

Researcher: Professor Ray Fitzpatrick
email: raymond.fitzpatrick@nuffield.ox.ac.uk

This research aims to provide a clear quantitative and qualitative evidence base for three progressive neurological conditions: Parkinson's Disease (PD), Multiple Sclerosis (MS) and Motor Neurone Disease (MND). It will give us a picture of current patterns of health, quality of life, access and experience of services, for individuals and their carers, so that progress in developing services can be measured.

The final report for this study is due by the end of this year. Updates can also be seen on the departmental website: (<http://www.publichealth.ox.ac.uk/units/hsru/PROGRESSIVE%20NEUROLOGICAL%20CONDITIONS/Intro>)

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

Researcher: Dr Sylvia Bernard
email: smb509@york.ac.uk

This project aims to identify what factors affect the development of integrated services for people with LTNC. Then, a benchmarking system will be designed, based on these factors, which will be used to assess whether the NSF for LTNC has influenced the way services have been integrated. The final report for this study is due by the end of this year.

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

Researcher: Dr Diana Jackson
email: diana.m.jackson@kcl.ac.uk

This study aims to increase our understanding of the problems faced by people who look after someone with a LTNC, in order to learn from their experiences what has helped, or would have helped. There is a particular interest in learning more about family members who have additional caring roles.

Long-term involvement in fitness enablement (LIFE) study (2006-2009)

Researcher: Dr Helen Dawes
email: hdawes@brookes.ac.uk

This research aims to establish how people would like to be supported to do exercises; to provide information on what community facilities currently exist that people with LTNC can use, and to determine whether exercise delivered in a leisure centre, combined with a physical activity support system (PASS), is effective.

The final report for this study is due by the end of this year.

Defining the palliative care needs of people with late-stage Parkinson's Disease (PD), Multiple System Atrophy (MSA) and Progressive Supranuclear Palsy (PSP) (2007-2010)

Researcher: Tariq Saleem
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This research sets out to gain better understanding of the experiences and needs of people severely affected by PD, MSA and PSP. The aim is to identify the most effective approaches to enhancing quality of life and providing flexible, personalised support from all quarters.

Quality Neurology (2007 - end of 2009)

Lead Applicant: Alun Davies, MS Society,
email: adavies@mssociety.org.uk

Quality Neurology is a project which has been set up to test a way of checking how well services meet the quality requirements (QR) of the NSF for LTNC, with a focus on what the QRs mean to service-users. It brings together the MS Society Parkinson's Disease Society, Motor Neurone Disease Association & Ataxia UK, in collaboration with the 'Integrated Services' research team at York University.

The final report from this study is due by the end of this year.

Review of Epidemiology and Service Use in Rare Long Term neurological conditions (RESULT) study (2009-2010)

Lead Researcher: Prof Cath Sackley
email: c.m.sackley@bham.ac.uk

The RESULT study is looking at service provision for people with rare long-term neurological conditions. Although the NSF for LTNC has targets to improve care and treatment, little is known about the types of services people receive. This study aims to investigate what services are currently provided to people with more unusual conditions and how they need to change to meet the targets set out in the NSF.

Carers of people with LTNC & respite/ replacement care (2008 – 2010)

Lead Applicant: Prof Lynne Turner-Stokes.
Researcher: Dr Diana Jackson
email: diana.m.jackson@kcl.ac.uk

People who look after a relative with a LTNC play a critical role in lightening the load on health and social services but often need to take a break. It can make a big difference, whether it involves someone else coming in to the home, or their relative being looked after in a residential setting. However, good quality care of this kind can be hard to come by. Currently, we do not know enough about what would be of most benefit for different people. This study aims to investigate this in order to develop improved services for the future.

A case study on the impact of inclusive practice in Neuro-Rehabilitation / Neuro-Psychiatry services (2008 -2010)

Lead applicant: Dr Tina Cook, Northumbria University
email: tina.cook@northumbria.ac.uk

The research team, backed by evidence from service-users, think there might be a link between how 'included' people with LTNC feel when they use the NHS and how this affects them. Much has been written about types of medical treatment people receive but there is nothing about the effects of 'feeling included' in the treatment process. This study aims to investigate the awareness, contribution, and effects of being included when receiving services and treatment.

Advisory Group News

The Advisory Group was established at the start of the initiative to provide advice and guidance on setting up and monitoring the research. Each member brings their specialist knowledge and expertise to help with making decisions about the priorities for the programme. The group meets twice a year and receives, and comments on, progress reports and research documents as they are produced. A smaller sub-group has overseen both commissioning and tendering processes for the initiative. Some members of the group have reviewed complementary research reports, such as the annual FAST report, noted in Publication News.

Research teams have an opportunity to meet the DH team and Advisory Group, each year as part of the reporting process. Presentations made at these meetings can be downloaded from www.ltnc.org.uk.

We are pleased to welcome the following new members to the group:



Marilyn Bentham joins us as ADASS representative. She is a social worker and manages a Disability Resource Team that supports people with complex needs.

Claire Guy has a neuro-physiotherapist's background, having worked with people with spinal injury, MS, stroke and brain injury. She chairs the Oxford branch of ACPIN (the special interest group of physiotherapists working in neurology).

Bairbre Kelly joins us from the Office of Disability Issues (ODI), part of the Department of Work and Pensions (DWP), and is currently on maternity leave. We have been pleased to meet Luke Staniland in her absence.



Dr Maggie Murphy is an occupational therapist. She is an associate member of the Society for Research in Rehabilitation and a member of the College of Occupational Therapists Specialist Section in Neurology.