

## The future for neurological conditions in Ireland: a challenge for healthcare an opportunity for change

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The Future for Neurological  
Conditions in Ireland:

A Challenge for Healthcare;  
an Opportunity for Change

2010 | Neurological Alliance of Ireland



NEUROLOGICAL ALLIANCE  
*of* IRELAND



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**NEUROLOGICAL ALLIANCE OF IRELAND**

THE FUTURE FOR NEUROLOGICAL CONDITIONS IN IRELAND:  
A CHALLENGE FOR HEALTH CARE; AN OPPORTUNITY FOR CHANGE

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NEUROLOGICAL ALLIANCE  
*of* IRELAND

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## Ministerial foreword



Over 700,000 people in Ireland affected by neurological disorders live daily with conditions which impact on every aspect of their lives. This impact is also felt by their families and their communities. As our population ages, and as new treatments become available, the care needs of people with neurological conditions are an important challenge for our health system.

As Minister for Health and Children, I recognise that neurology has made a significant contribution to innovation in healthcare in Ireland, focusing on how services can be delivered closer to patients and in multi-disciplinary teams that respond to patients as people. I have seen neurology lead in areas such as the use of telemedicine, assistive technology and rehabilitation. I have been impressed with the models where specialists act more as a resource to primary care so they can manage neurological symptoms in a way that is more convenient for patients. Recognising the growing importance of this area significant investment has been made into the development of neurology services. The forthcoming National Neuro-Rehabilitation Strategy will provide a further step to meet the needs of those with progressive and disabling neurological conditions. It will seek to address a very centralised service with a model that links national expertise more comprehensively with regional and community provision. It will seek to push for voluntary sector provision to be reconfigured to cut down duplication of service provision and particularly of back room staff and for them to move from disease specific provision to provide better for all patients with needs in a given area.

This important publication by the Neurological Alliance of Ireland is unique in bringing together a wide range of stakeholders to identify the valuable services and expertise currently provided within the health system to neurology patients and their families. There is recognition of the significant opportunity provided by health care reform and changes in practice to deliver real improvements in the quality of care for people with neurological conditions in this country. It also highlights the challenges and opportunities for the neurological services into the future.

I recognise the work of the Neurological Alliance of Ireland as a key partner with my Department in this area. Through its publications and activities, including the Standards of Care documents and the development of National Brain Awareness Week, the NAI continues to inform and influence the debate on neurological care in this country. I recognise this publication as an important contribution in our journey together and pay tribute to work of all the organisations under the NAI umbrella.

A handwritten signature in black ink, appearing to read 'Mary Harney', written over a horizontal line.

**Mary Harney TD**  
Minister for Health & Children

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## **The Neurological Alliance of Ireland**

The Neurological Alliance of Ireland (NAI) is the umbrella organisation representing non-statutory organisations working with people with neurological conditions in Ireland. The aim of the NAI is to promote the development of services and supports for people with neurological conditions, their families and carers. The NAI works to highlight the needs of people with neurological conditions throughout Ireland by contributing to policy development, participating in consultation, holding seminars and conferences on key issues in relation to neurological care and organising an annual programme of events for National Brain Awareness Week. The work of the Neurological Alliance of Ireland is supported by the Department of Community Rural and Gaeltacht Affairs.

Non-statutory organisations that are directly involved in the support of people with neurological conditions can be considered for ordinary membership of the NAI. Individual and associate membership is also available.

Contact details for the NAI, and its member organisations are featured at the end of this document

The Board of the Neurological Alliance of Ireland has commissioned and supported this initiative on behalf of the organisation.

### **The Board is made up of representatives of member organisations as follows:**

Chair: Anne Winslow (Multiple Sclerosis Society of Ireland)  
Vice Chair: Barbara O'Connell (Acquired Brain Injury Ireland)  
Treasurer: Maurice O Connell (Alzheimer Society of Ireland)  
Honorary Secretary: Laura Keane (The Rehab Group)  
Ann Keilthy (Parkinson's Association of Ireland)  
Patricia Towey (Huntington's Disease Association of Ireland)  
Karen Pickering (Muscular Dystrophy Ireland)  
Kieran Loughran (Headway)  
Patrick Little (Migraine Association of Ireland)  
Aisling Farrell (Brainwave The Irish Epilepsy Association)

## **Acknowledgments**

The Neurological Alliance of Ireland (NAI) wishes to thank all the authors who contributed their experience and expertise to this publication, and by so doing increase our awareness and understanding of neurological care in Ireland. We thank the individuals living with neurological conditions who, through their testimonials, provide us with a unique insight into the impact of these conditions on the day-to-day lives of those affected by them. The support of the Minister for Health and Children, Mary Harney, TD, and Dr Philip Crowley, Deputy Chief Medical Officer of the Department of Health and Children for this initiative is particularly acknowledged.

We would like to thank our member organisations and supporters for their assistance on this project and for their continued commitment to the NAI since its establishment.

We would like to pay particular tribute to the members of the Editorial Committee, the Chairperson and the Board of NAI for their work in preparing this publication. The members of the NAI editorial committee are as follows:

Ms Laura Keane, The Rehab Group (Chair of the Editorial Committee)  
Ms Magdalen Rogers, Neurological Alliance of Ireland (Publication Director)  
Ms Barbara O'Connell, Acquired Brain Injury Ireland  
Ms Taragh Donohoe, Multiple Sclerosis Society of Ireland  
Ms Aisling Farrell, Brainwave The Irish Epilepsy Association  
Ms Ann Keilthy, Parkinson's Association of Ireland

This initiative was supported by a grant from the Medtronic Foundation.

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## Executive Summary

The aim of this publication is to contribute to a greater understanding of the challenges facing neurological care in Ireland and to call for a strategic focus on implementing solutions to these challenges within our health service.

It is estimated that over 700,000 people in Ireland live with a neurological condition, representing approximately 17 per cent of the total population of Ireland. These conditions include acquired brain injury, epilepsy, multiple sclerosis, stroke, Parkinson's disease, dementia and other progressive, intermittent or disabling conditions of the brain or spinal cord. Neurological conditions can impact the physical, intellectual, emotional, social and economic life of the person and their family.

In 2006, the World Health Organisation (WHO) reported that neurological conditions account for a substantial disease burden worldwide, which is greater than that represented by digestive diseases, respiratory disease and malignant neoplasms (tumours). Europe-wide the cost of neurological disorders (excluding dementia) is estimated to be €84 billion, with dementia costing another €55 billion. This represents a total cost of €139 billion. To put this in perspective, the total cost associated with respiratory disease in Europe is €102 billion.

Currently, there are no reliable ways of measuring the disease burden of neurological conditions in Ireland. However, there are some key indicators that these conditions place significant demands on the Irish health care system. Nationally, approximately 23 neurologists serve those with neurological conditions, little over half of the recommended number for our population. Twenty per cent of A&E admissions are neurological in nature and often occur due to a lack of outpatient capacity. The mortality rates from stroke are larger than that for breast, bowel and lung cancer put together.

From a patient perspective there are many significant problems to accessing services to adequately manage their condition. Many people experience long delays in accessing specialist neurological or rehabilitative services, significantly impacting on long term outcomes and level of disability. There are ongoing challenges for the Irish health care system in meeting the needs of people with neurological conditions. A series of Standards of Care documents developed by the Neurological Alliance of Ireland (NAI) between 1999 and 2002 presented a comprehensive outline of their unique requirements across all areas of health service provision. Nearly 10 years on from their publication, Ireland continues to lack a strategic focus on improving neurological care.

In recent years there has been some investment in neurological services and an increased recognition of the need for strategic planning in this area through the commissioning of a number of reports and the development of a national strategy for neurorehabilitation. However, much of this work is currently unpublished, there are ongoing gaps in the provision of care and significant unmet need.

Despite these challenges, Ireland has a unique opportunity at the present time to develop a health service that can respond to the needs of people with neurological conditions. We have at our disposal a number of key factors that have the potential to significantly improve the quality of life of these individuals and their families: the expertise and commitment of a range of service providers (statutory and non statutory); the benefits of increasing research to inform best practice in neurological care, and a legislative framework which identifies and promotes the needs of those with disabling conditions.

In order to take advantage of these opportunities and overcome the significant challenges in providing for the needs of people with neurological conditions now and into the future, there is an urgent requirement for a strategic focus on improving neurological care within the health service. Only by a concerted emphasis, long overdue, on this area of our health system can we ensure the delivery of the highest standard of care for all those affected by neurological conditions in this country.



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## Recommendations

The NAI is an advocate for those living with neurological conditions and the non-statutory organisations that support them. We have been closely involved in each of the strategy documents prepared in recent years and frequently consult with all stakeholders involved in the provision of neurological care in Ireland. In that regard, we are calling on the government and the Health Service Executive (HSE) to develop a comprehensive response to neurological care within our health service, which will require:

- the need to implement the existing recommendations in this area, including the Strategic Review of Neurology and Neurophysiology Services and the National Neurorehabilitation Strategy, to create a network of neurospecialist services and personnel which can respond to current and future demand;
- the need to change and improve the way in which services are delivered in order to address the range of needs of the person with a neurological condition across all areas where they come into contact with the health services
- a clear commitment to prioritising neurological care in Ireland through target setting and year-on-year development plans based on a recognition of the continuing unmet need in this area and emerging demographic trends;
- the need to support and strengthen the role of the Neurological Alliance of Ireland as a partner in the development of policy and improvement of practice in neurological care.

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## Introduction

The Neurological Alliance of Ireland's (NAI) Standards of Care documents (1999-2002) represented a pioneering initiative to examine and document, for the first time, the unique requirements of people with neurological conditions within the health services. Until then, the impact of these conditions on individuals and their families, and their need for specialised services and supports, was poorly understood and appreciated. A group of health professionals and non-statutory organisations came together, under the NAI umbrella, to develop a series of detailed recommendations for the Irish health system.

Since then, the NAI has continued to work together with its member organisations and with the support of all those involved in the delivery of services and supports for people with neurological conditions, to highlight the need to improve neurological care in this country. A key partner in the Strategic Review of Neurology and Neurophysiology Services carried out by the HSE, and in the National Neurorehabilitation Strategy, the NAI has established a strong voice as the representative umbrella for non-statutory organisations in Ireland.

Nearly 10 years on from the Standards of Care, there is increasing recognition of the needs of people with neurological conditions as a distinct group within the health service. A series of reports have examined specific areas of service provision, including acute neurology, neurosurgery and neurorehabilitation. We are also at a time of critical change and reform within our health system.

The NAI has considered it appropriate, at this time of change, to bring together a range of contributors to focus on neurological conditions as both a challenge for health care in Ireland, and an opportunity for change.

A wide range of clinicians, academics and representatives from statutory and non-statutory organisations in health and disability in Ireland have come together to bring their expertise and experience to bear on this issue. The result is a broad-ranging document, which reflects the changes that have occurred in the provision of health and social care services for people with neurological conditions in the last decade, the significant gaps that remain and the opportunities and solutions that are available to us. Most importantly, the views of people with neurological conditions are reflected throughout this publication through their personal testimonies introducing each chapter, reflecting on their own experiences and the changes that would make the most difference to them in their lives.

This document is aimed at providing all those working in the design and delivery of health and disability services in Ireland, a greater understanding of the needs of people with neurological conditions. It also aims to provide an appreciation of the urgent requirement to prioritise the response to these needs in the context of the reform and development of our health service. It gives a unique and timely insight into many of the challenges facing this area of health care, now and into the future, as well as the opportunities that are provided by research and innovation in health care practice. This publication is about proposing solutions as much as it is about outlining problems. It recognises the expertise, commitment and consensus that exist among stakeholders in this area in Ireland, and their ability to respond flexibly and creatively to the needs of people with neurological conditions. One only needs to examine the successful entries to Irish health care awards programmes over the past number of years to see that initiatives for people with neurological conditions are well represented, despite the relatively small numbers of specialist personnel working in this area of the health services.

As we move into a new decade, it is now time to face the challenge of developing a response to the needs of people with neurological conditions within our health service. Our aim is that this publication will focus attention on the need to prioritise neurological care in Ireland through developing a framework of specialist services and expertise as recommended in a series of reports in this area, changing and improving the way we deliver services and engaging in a partnership with all stakeholders involved, including the NAI.

We would like to take this opportunity to thank all those who have given their support and commitment to this project. We would like to extend our warm appreciation to all the contributors to this publication, including the member organisations of the NAI. Most especially, we thank those people living with neurological conditions who have given us their unique personal testimony to develop and strengthen our understanding and appreciation of the true impact of these conditions on individuals and their families.

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## **How to read this document**

This publication aims to bring together and highlight in one document the expertise and experience of a wide range of people involved in the area of neurological care in Ireland, whether in research, clinical practice, policy development or service provision and support. It stresses that the time has come to prioritise and resource the development of services for people with neurological conditions in this country.

This publication is intended to cover the full spectrum of neurological conditions, including dementia, stroke and acquired brain injury, which are not always considered under this umbrella term. It is not intended to document the entire complex range of health care needs of people with neurological conditions; notably, areas such as preventative aspects of neurological conditions, genetic testing and counselling, palliative care, mental health needs and the experiences and requirements of family carers are not specifically addressed in this publication.

It is important to note that the needs of children and older people with neurological conditions are not addressed within this document as their specific experiences require a level of detailed examination, which lies outside the scope of this publication.

We are also keenly aware that the document does not address many important aspects of living with a neurological condition in Ireland, including barriers to education, transport, social inclusion and the lack of awareness and stigma associated with many of these conditions. The NAI Standards of Care should be referred to for a detailed examination of these areas.

It is important to note that this publication is not intended to promote one particular approach, intervention or response over another, or provide a comprehensive understanding of specific neurological conditions. The views conveyed in the chapters should be understood as the opinions of individual contributors and do not necessarily reflect the position of the NAI.

The personal testimonies contained in this document are expressed in the individuals own words to reflect their experiences of living with a neurological condition.

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<b>Figure 1.4:</b> <b>Source:</b>	Possible managed care pathway for epilepsy Dr Colin Doherty



**PART I**  
**THE CHALLENGE**

**Chapter 1:** Neurological conditions:  
A challenge for the Irish health system

Professor Orla Hardiman

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“I live in Co. Waterford and my neurologist and neurosurgeon are based in Dublin, which means I have to travel 142km to see them. I get a very early train which means I get up at 4:45am and get home 5:30pm. Because of tiredness I will have seizures on the train to and from Dublin and all night in my sleep.”

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## **Chapter 1. Neurological conditions: A challenge for the Irish health system**

### **Prof Orla Hardiman**

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#### **Introduction**

“There is ample evidence that pinpoints neurological disorders as one of the greatest threats to public health.”  
(World Health Organisation (WHO), 2006)

Clinical neurology is concerned with the prevention, diagnosis, treatment and continuous assessment and care of patients with diseases of the central and peripheral nervous system, including disorders of the muscles. Neurology has been considered in the past to be an elite and academic specialty, where diagnostic acumen was highly valued, and the prospect for therapeutic intervention limited. However, as communicable diseases decline, neurological disease, cancer and cardiovascular disease are of increasing concern from a population health perspective.

Neurological diseases range from those that are invisible but quality-of-life threatening (e.g. epilepsy, migraine etc.) to those that are associated with severe and progressive physical and/or cognitive decline (e.g. motor neurone disease and Alzheimer’s disease). Neurological conditions affect all age groups from the young to the economically active and older people. While some neurological conditions are easily recognisable such as migraine or advanced Alzheimer’s disease, others can be difficult to diagnose such as atypical dementias or early motor neurone disease. However, the majority are long-term conditions.

#### **Prevalence of neurological conditions**

Neurological diseases are common – one billion people are currently affected worldwide, and the incidence of neurological conditions is increasing as our population grows and ages. The WHO has recognised the growing challenge for health systems of managing neurological conditions, with the need to develop specialist services for diagnosis, treatment and rehabilitation. The WHO’s 2006 report *Neurological Disorders: Public Health Challenges*, found that neurological conditions account for a substantial disease burden worldwide, which is greater than that represented by digestive disease, respiratory diseases and malignant neoplasms i.e. tumours. Deaths from neurological disorders are an important cause of mortality and constitute 12 per cent of total deaths globally. Neurological conditions are also very significant in terms of YLDs (years of healthy life lost as a result of disability) contributing to over 14 per cent of YLDs globally by 2030. For developed countries, including Ireland, the percentage of people developing neurological conditions associated with ageing (including Alzheimer’s disease, Parkinson’s disease etc.) is set to increase substantially by 2030.

Neurological conditions have significant implications for our society, for the individuals and families affected by these conditions, for health systems providing care for them and for the wider economy. The *Cost of Disorders of the Brain in Europe* study (Andin-Sobocki et al., 2005) estimated that the cost of neurological disorders across 28 European countries (excluding dementia) is €84 billion, with dementia costing €55 billion. This represents a total of €139 billion. In comparison, the total costs associated with respiratory disease in Europe are €102 billion (European Respiratory Society and European Lung Foundation, 2003). Much of the costs associated with neurological conditions are indirect i.e. loss of ability to work either in the short or long term. The authors note that neurological conditions receive a low proportion of direct expenditure on health care, despite the significant long-term disabling impact and very high indirect costs of these conditions.

#### **Measuring the impact of neurological conditions in Ireland**

There is currently no reliable way of measuring the true burden of neurological conditions within the Irish population. Current health service measurement systems all have significant shortcomings in providing accurate statistics on the number of people living with neurological conditions in Ireland. The National Physical and Sensory Disability Database (NPSDD) provides valuable in-depth information on the needs and experiences of those individuals with disabling neurological conditions in Ireland who are registered on the database (Health Research Board, 2008). However, registration on this database is entirely voluntary and it was never intended to act as a measure of prevalence of neurological conditions in Ireland. Just how significantly the database underestimates the true prevalence of specific neurological conditions can be seen in the panel, which outlines the first national prevalence study of epilepsy in Ireland (Brainwave and University College Dublin (UCD) Centre for Disability Studies, 2009).

**Case Example:** Limitations of current data systems to reflect the prevalence of neurological conditions in Ireland

No epidemiological data on the prevalence of epilepsy currently exists in Ireland. Brainwave The Irish Epilepsy Association commissioned the UCD Centre for Disability Studies to determine the prevalence of this condition in Ireland. Brainwave requested that the prevalence study be conducted at nationwide level, and that the scope of the study include both children and adults. This study is the first nationwide prevalence study of epilepsy anywhere in Europe, and provides previously unavailable data on epilepsy in Ireland. Having investigated five different nationwide sources of data, the study provides a comprehensive assessment of prevalence, estimating that there are 33,032-36,844 cases of treated epilepsy in those over the age of five years. These figures are in stark contrast to the figures that are captured by the NPSDD. It was stated in the NPSDD Committee Annual Report 2008 that 618 people with epilepsy have registered on the database.

Very few such large scale incidence and prevalence studies on specific neurological conditions have been carried out in Irish populations. The Population Health Directorate of the HSE, in an, as yet, unpublished report on neurology services in Ireland (HSE, 2007), carried out a review of international statistics to provide the following estimates of the number of people living with neurological conditions in Ireland and future projections (Table 1.1 below)

**Table 1.1 Estimated numbers of persons with neurological conditions in Ireland**

	UK Neuro-Numbers Report	2006 CENSUS 4.235m	CSO Population Projection		
			2011 4.488 m	2016 4.811 m	2021 5.070 m
Persons living with the condition	17%	725,987	762,960 (17%)	824,743	869,143
Help with daily activities	0.6%	25,410	26,928 (0.6%)	28,866	30,420
Disabled by condition	2%	84,699 (2%)	89,760	96,220	101,400
Has condition but able to manage life on daily basis	14.5%	615,879	652,683 (14.5%)	699,657	737,323
Number of newly diagnosed each year	1%	43,559	44,880 (1%)	48,110	50,700
People caring for person with condition	1.5%	61,709	66,038 (1.5%)	70,790	74,601

Source: Health Service Executive, 2007. *Strategic Review of Neurology and Neurophysiology Services in Ireland*. Ireland: Unpublished report

The following estimates of the numbers of people living with specific neurological conditions were provided for this report by members of the Neurological Alliance of Ireland (NAI) (**Table 1.2 below**)

**Table 1.2:** Estimated numbers of people with specific neurological conditions in Ireland

NEUROLOGICAL CONDITION	NUMBER WITH THE CONDITION IN IRELAND	SOURCE OF INFORMATION
Acquired brain injury	30,000	National Health Service, 2005. <i>National Service Framework for long term (neurological) conditions</i> . England: Department of Health UK. (Information provided by Headway)
Alzheimer's disease and other types of dementia	37,746	O'Shea, E Prof, 2007. Implementing and other types <i>Policy for Dementia Care in Ireland</i> . Ireland: The Alzheimer Society of Ireland; Irish Centre for Social Gerontology, National University of Ireland, Galway.
Epilepsy	37,000	Linehan, C; Kerr, M P; Walsh, P N; Brady, G; Kelleher, C; Delanty, N; Dawson, F; Glynn, M, 2009. 'Examining the prevalence of epilepsy and delivery of epilepsy care in Ireland'. <i>Epilepsia</i> , published online.
Huntington's disease	400-500	Green A Prof, National Centre for Medical Genetics, Our Lady's Hospital, Crumlin.
Migraine	622,000 (14.3 per cent in adults aged 18-65 years and geographical differences in migraine are not marked)	Steiner, T J et al., 2003. 'The prevalence and disability burden of adult migraine in England and their relationships to age, years and gender and ethnicity'. <i>Cephalalgia</i> , 23 (7): 519-527  Stovner L J et al., 2006. 'Epidemiology of headache in Europe'. <i>European Journal of Neurology</i> , 13 (4): 333-45.
Motor Neurone Disease	250	Irish Motor Neurone Disease Association
Multiple Sclerosis	8, 000	Tubridy N Dr, Consultant Neurologist, St Vincent's Hospital, Dublin
Muscular Dystrophy	556	Muscular Dystrophy Association
Myasthenia Gravis	350	Myasthenia Gravis Association
Neural Tube Defects:	0.8 - 1.5 in every 1000 births (2001) /Approximately 1 in every 1000 births.	Food Safety Authority of Ireland, 2006. <i>Report of the National Committee on Folic Acid Food Fortification</i> . Dublin: FSAI. Also Eurocat Registries Network - <a href="http://www.eurocat-network.eu">www.eurocat-network.eu</a> .
Parkinson's Disease	6,000-7,000 (1000 over 80; 20-30 per 1000)	(2-3 per 1000 over 60 years of age; 10 per Hauser R (ed), 2006. <i>Parkinson's disease questions and answers</i> . 5th ed. Florida: Merit International Publishing.
Post Polio	4200	Hart, J, 1996 <i>Irish prevalence estimated for post polio support group</i> , Dublin. Comparative studies: Ahlstrom G et al., 1993. 'Epidemiology of neuromuscular disease, including post polio sequelae, in a Swedish County'. <i>Neuroepidemiology</i> , 12 (5): 262 - 9. Pentland, B et al., 1999. <i>Survey of the Late Effects of Old Polio in Lothian Scotland</i> . Edinburgh: Rehabilitation Studies Unit, Astley Ainslie Hospital.
Progressive Supranuclear Palsy	250	Information supplied by Progressive Supranuclear Palsy Association.
Syringomyelia	1 in 10,000	Lynch, T Prof. <i>In a communication to Syringomyelia Support Group</i> . Dublin: Mater Hospital

Source of table: Neurological Alliance of Ireland

Additional note by Prof Orla Hardiman: The total number of people with motor neurone disease in Ireland at any one time is 200-205 (O'Toole et al., 2008)



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These stark numbers stress the extent of this growing demographic within the Irish health services and the critical need for the development of neurological services to cope with current as well as increasing demand.

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### **The reality of an ageing population**

As the Irish population grows and ages, the prevalence of age-related neurological diseases is set to rise at a rate that is higher than our European counterparts. It is estimated that within the coming 20 years, the prevalence of cognitive decline in Ireland will increase by at least 230 per cent. In the absence of disease modifying therapies, an increasing population of individuals with cognitive impairment is likely to strain the resources allocated to health care for the elderly. And as new treatment strategies are developed, an infrastructure will be required to identify and treat those affected. Limiting the progression of neurodegenerative disease, or indeed reversing the devastating effects, will have an enormous impact on the health status of older individuals, and providing an adequate infrastructure to enable this will be beneficial to the community at large from a health economic and social perspective.

### **Challenges for the health services: the need for integrated care**

*Develop integrated services across all stages of the care journey (Priority 1: HSE Transformation Programme 2007-2010)*

Advances in the management of neurological conditions of younger- and mid-life have also placed an increased demand on existing services as new therapies become available. Multiple sclerosis, epilepsy, migraine and other common conditions have a severe impact on the quality of life and economic potential of affected individuals, their families and their communities. New treatments have the potential to significantly reduce disability and enhance quality of life. But access to specialist services is severely limited, and optimal management is accordingly curtailed in a significant proportion of the population. In some instances, such as multiple sclerosis, failure to treat people in the early phase of the illness can lead to increased disability in later years. Similarly, suboptimal management of epilepsy in early life can also lead to greater difficulty in achieving seizure control later on, and increased neurological disability of all types has an adverse effect on all aspects of life.

Neurological care requires a combination of acute hospital-based interventions (for emergency neurological conditions including stroke, meningitis, severe epilepsy etc) and well supported outpatient based services integrated with community care. At present, up to 80 per cent of all admissions to public hospitals in Ireland occur through A&E departments. Up to 20 per cent of these are neurological. While a proportion are due to 'brain attack'(stroke), and require high technology stroke units similar to coronary care units, many represent exacerbations of underlying chronic neurological conditions, or conditions that could be managed in an outpatient setting if services were easily accessible and waiting lists short. A reconfiguration of services is urgently required to cater for these types of conditions. There is considerable evidence to indicate that the most effective type of care is provided by a multidisciplinary team, led by neurologists and including a wide range of clinical professionals such as specialist nurses, physiotherapists, occupational therapists, speech and language therapists and social workers. Liaison between hospital and community based services is key to the success of these efforts to ensure a seamless transfer of care from the acute (hospital-based) to the chronic (community-based) phase of management.

*"Providing neurological care through primary care requires significant investment in training primary care professionals." (WHO, 2006)*

Support for the development of multidisciplinary services in the community for the management of chronic disease is a key aspect of the HSE Transformation Programme. The initiative provides a framework for the management of long-term chronic conditions in the community, through effectively resourced primary care teams liaising with specialist expertise in neurological conditions, in health and social care networks. It provides a unique opportunity to improve delivery of services to people with neurological conditions in Ireland.

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An adjustment in budget allocation within the health system, such that funding 'follows the patient' were it to be truly effective, would be of significant benefit to people with neurological conditions, most of whom can continue to live independently in their own homes with adequate support and for whom hospital admissions are an inappropriate setting for the management of their condition.

Ireland currently lacks a properly resourced, integrated framework for the management of neurological conditions in the community. This compounds the problem of 'delayed discharges' within acute hospitals, with an attending knock-on effect on A&E capacity and general hospital efficiency. Inadequately funded community services lead to over-dependence on hospital-based neurology services to manage the ongoing needs of people with neurological conditions once they have been discharged.

This is exactly the type of situation that the Transformation Programme has been developed to address. Neurological conditions provide the ultimate 'test case' for the success of measures to improve integrated care through all stages of the patient journey.

### **The challenge of age-related discrepancies in service provision**

*"Equity will be central to developing policies ... to ensure equitable access to services based on need." (Department of Health and Children, 2001)*

The principle of equitable access to health services is a vital one for people with neurological conditions but their experience is often one of inequity. Our health service has developed around traditional age-related categories, children's services for those under 65 years, adults-to-65 years, and older age services for those over 65 years of age. Services for people with a disability experience a distinct cut off at the age of 65 when they come under older people's services and are no longer entitled to access disability services. These arbitrary cut off points are inappropriate for people with long-term neurological conditions and represent a significant obstacle for the delivery of integrated care to meet the needs of the person over time. They represent a source of distress and anxiety to people with neurological conditions and their families and frustration to service providers.

### **Conclusion: An opportunity for change**

*"Policy-makers and health-care providers may be unprepared to cope with the predicted rise in the prevalence of neurological and other chronic disorders and the disability, resulting from the extension of life expectancy and ageing of populations globally." (WHO, 2006)*

There is an urgent need to develop neurological services in Ireland. As the population ages, the burden of neurological disease will increase on the Irish health system. Acute neurological care must be developed as a matter of priority. 'Brain attack' should carry the same sense of urgency as 'heart attack'. For more chronic neurologic disease, it must be recognised that the vast majority of people who use the public health service could be managed by a combination of high quality primary and specialist secondary care. Multidisciplinary teams must be put in place in both the hospital and community for the diagnosis, rehabilitation and long-term management of neurological conditions. If the private sector is to be harnessed to provide health care, there should be an emphasis on those people with ongoing needs as a result of chronic disease who will not be catered for by private facilities. Finally, there is a critical requirement for improvements in data gathering systems in our health services to enable the effective planning of services in response to need.

## Profiles of specific neurological conditions in Ireland

The historical management of stroke, dementia and acquired brain injury within our health service means that these conditions are not always understood to be covered under the umbrella term of neurological conditions in this country, despite the fact that they represent a significant proportion of those whose lives are impacted by neurological disability. In order to promote an understanding of these conditions within an overall context of the need to improve neurological care in Ireland, they will each form the subject of a specific focus below.

## Stroke

Dr Joe Harbison, Consultant Stroke Physician, St James's Hospital and Secretary of the Irish Heart Foundation Council on Stroke and Ms Imelda Noone, Advanced Stroke Nurse Practitioner, St Vincent's University Hospital

*(Both authors are contributing on behalf of the Irish Heart Foundation Council on Stroke.)*

Approximately 10,000 people experience stroke every year in the Republic of Ireland (ESRI, 2007). The Irish Heart Foundation estimates that over 30,000 people in Ireland are living with stroke. Heretofore Irish stroke services have been poorly structured and resourced. The lack of reliable Irish data on stroke incidence, prevalence, associated morbidity and mortality, has had a knock-on effect on the failure to develop stroke services in both acute and community settings.

Stroke can be associated with considerable physical, communicative, cognitive (thinking and memory abilities), emotional and social changes. It often brings with it considerable emotional, psychological and social, communicative and physical consequences. However, modern management and support offers huge advances on previous possibilities, and it is hoped that the development of a National Stroke Strategy will bring huge advances for all those affected by stroke.

Acute stroke morbidity, mortality and long-term prognosis are significantly improved if persons with stroke admitted to hospital are cared for in stroke units. This is accepted internationally as the expected 'standard of care', and reduces mortality by 20-25 per cent with the number needed to be treated being 14 to prevent one death or high-dependency outcome.

Every general and regional hospital in Ireland must have a stroke unit as part of an expert stroke service, which will deal with all aspects of care, from initial presentation, assessment and treatment right through to completion of rehabilitation and further follow up as required. Only in this way can individuals with stroke in Ireland, similar to their counterparts elsewhere in the developed world, be guaranteed the improved outcomes in terms of morbidity, mortality and functional status that are associated with stroke units and service care.

Stroke unit care may vary from hospital to hospital and may encompass both acute and/or rehabilitation management. The stroke unit in each hospital must have an adequate number of ring fenced beds in a geographically defined location, have proper multidisciplinary staffing levels and have adequate capacity for acute physiological monitoring [to include non-invasive blood pressure, ECG, oxygen saturation, temperature, blood glucose etc.].

In Ireland, we are facing a significant increase in the number of older persons in the coming decades. Their care needs must be planned for now. The number of over 80s, in particular, is going to increase dramatically. Many people with stroke have multiple existing medical co-morbidities and complex care needs following stroke. Many require extended acute medical intervention and expertise and high level para-medical, allied health professional and nursing input for several weeks in a stroke unit, following their stroke.

Adequate hospital bed capacity and specialist staffing levels are paramount to maximising functional outcomes and to minimising need for long-term care placement. All general hospitals should provide a stroke service, and all require core diagnostic infrastructure to include standard CT, carotid imaging, trans-thoracic echocardiography and 24-hour ECG recording.

Between 5 and 30 per cent of patients in leading international centres are treated with emergency thrombolytic therapy for stroke (clot-busting) in the setting of a stroke unit. The treatment depends on the degree of stroke service development and level of education of the public. This treatment reduces mortality and disability with an efficacy equivalent to the impact of the acute stroke unit care itself. It is recommended by expert international bodies, and is rapidly becoming best practice internationally. It should be available to all patients in Ireland irrespective of where they live, and on a 24/7 basis.

Stroke is the third leading cause of death and the leading cause of acquired severe physical disability in Ireland, with at least one in five Irish people suffering a stroke in their lifetime. Every year more than 2000 Irish people die of stroke; it is estimated that about one in four of these deaths could be avoided if people were cared for more effectively. Stroke can affect anyone, and each year more than 10,000 Irish people suffer a stroke, while 30,000 Irish people live with stroke related disability.

The Stroke Council of Ireland launched The Stroke Manifesto in December 2009, a 16-point document calling on the government to radically improve the care of people with stroke by:

- implementing public education programmes to teach people how to reduce their stroke risk;
- commencing a public information campaign to help people recognise the signs of stroke;
- ensuring that all hospitals admitting stroke patients have a properly established stroke unit;
- helping develop a network of units to permit countrywide availability of specialist care for people having suffered a stroke;
- urgently implementing 24/7 thrombolysis services nationwide;
- equipping and training emergency services to deal with stroke;
- appointing more specialist stroke physicians to care for stroke patients;
- providing consultant-led, seven-day, rapid access neurovascular clinics nationwide;
- giving all stroke patients the entitlement to adequate specialist rehabilitation services to help them recover from stroke;
- guaranteeing the right of every stroke patient to a timely and planned transition from hospital to their home or long-term care based only on need and not because of inadequate supports;
- appointing regional stroke co-ordinators with responsibility of ensuring that patient needs are delivered;
- eliminating age discrimination from stroke services;
- adopting a charter to inform stroke patients of their entitlement in respect of treatment, care and rehabilitation;
- prioritising the development of a national stroke register;
- providing vocational opportunities and stroke group support for all;
- specifically addressing the needs of carers of stroke patients.

## Dementia

Prof Eamon O'Shea, Professor in Economics, NUI Galway and Director of the Irish Centre for Social Gerontology.

Dementia is an acquired syndrome of decline in memory and other cognitive functions that affects daily life in older people, mainly through diminished cognitive and functional capabilities (American Psychiatric Association, 2000). In the early stages of dementia, the person can live independently and is often not diagnosed for several years, if at all, after the onset of symptoms. As the disease progresses, it is difficult for people to cope on their own; care and supervision requirements increase, and, for many people, admission to long-stay care is necessary. Dementia affects an estimated 6.4 per cent of all persons aged 65 years and older, based on a major study of prevalence of dementia undertaken in eight European countries (Lobo et al., 2000). In recent years, dementia has become a major policy issue in all countries, given the numbers affected and the cost of care. The economic and social implications are significant for people with the disease, their families and the health and social care system, and will increase along with the ageing of the population.

An application of European prevalence rates for dementia to the most recent Census data in Ireland suggests that there are 39,000 people with dementia in the country. The majority of these people are looked after in their own homes, mainly by family members. The contribution of families to the care system is in contrast to the relatively low provision of community care for people with dementia in the country. Generally, people with dementia do not come into contact with the health and social care system until a crisis occurs, involving the person with dementia, their carer, or both parties. There is evidence to suggest that the weakness of community care has affected the wellbeing and quality of life of people with dementia and their families in ways that would, in any other area of the health service, lead to a public outcry (O'Shea, 2003).

Increased support for people with dementia in long-stay care is also necessary. Specialised dementia units are currently lacking, while some form of dementia-specific provision is necessary in all long-stay units. Accommodating people with dementia in residential care may require the hiring of new specialist staff, dementia training for existing staff and improved design of the built environment. The care process within long-stay facilities also needs to be improved. In particular, psychosocial approaches are required to complement medical and neurological models of service delivery. There should be more emphasis on developing meaningful communication with patients, using all of the senses, through reminiscence, music and various therapeutic and other time-intensive activities.

Because of the impact of demographic ageing in the coming decades and the severity of the disease burden, dementia must be accorded much higher priority in resource allocation in Ireland. For real progress to happen, dementia must be made a national health priority, similar to what happened for cancer and heart disease. A new Dementia Strategy should encompass four key strategic elements: early intervention, education and training; enhanced community-based services for people with dementia and their carers; co-ordination and integration of multidisciplinary care provision; and quality residential care that is centred on the person with dementia. A major investment in resources for dementia, focusing on the needs and capabilities of people with dementia living at home and in long-stay care settings, would yield rich dividends for all of us.

## Acquired Brain Injury

**Barbara O'Connell**, MBA, Dip COT, Co-Founder and Chief Executive of Acquired Brain Injury Ireland (formerly the Peter Bradley Foundation).

Acquired Brain Injury (ABI) can affect anyone at any time. ABI is an inclusive category that embraces ABI of any cause, including road traffic accidents, assault, aneurysm, viral infection (e.g. meningitis, encephalitis), cerebral anoxia, home or workplace accident, fall, brain haemorrhage and vascular accident (stroke or subarachnoid haemorrhage) and other toxic or metabolic insult (e.g. hypoglycaemia).

ABI has been described as a silent epidemic. It is for life, and the needs of the individuals affected change over time. Many people who acquire a brain injury are unable to resume their previous lives or return home. Brain injury can impact physically, psychologically, behaviourally and socially in a number of ways, including affecting memory, speech and language, mobility, sight, judgement and understanding of situations. It can also lead to reduced ability to concentrate, cope under pressure and to organise one's own life and finances. Subtle changes in personality too are common. These effects in turn lead to isolation and depression for the person with ABI. They can also place significant pressures on carers and families, including financial and emotional strain.

Each year in Ireland up to 11,000 people are admitted to hospital with a head injury with a further 10,000 suffering from a stroke (ESRI, 2007). Additionally, ABI Ireland estimates that up to 35,000 people in Ireland between the ages of 16-65 have an ongoing disability as a result of a brain injury. Brain injury is the foremost cause of death and disability in young people. Those who are between 15-29 years of age are three times more likely to sustain a brain injury than any other group. Due to medical and technological advances many are now surviving who heretofore would have died. Those affected by ABI have a normal life span. Of those who acquire a brain injury in any year, three quarters are between the ages of 18-35 and 75 per cent are men.

Identification of incidence and prevalence of ABI is fraught with difficulties. Some studies report figures for stroke, some for traumatic brain injury while others use a generic ABI category. Most studies carried out since 1991 have used local rather than global samples. Statistical data is based solely on hospital admission, and there is no standard method of data collection. Failure to record diagnosis is common. In a 1996 study, of 107 patients admitted to a district hospital, 47 had a head injury with only 23 recorded as a diagnosis (Moss and Wade, 1996). Failure to record diagnosis is more likely in the presence of other more severe injuries and inpatients with minor or trivial injuries. Consequently, Hospital Inpatient Enquiry (HIPE) figures are likely to significantly underestimate the number of ABIs.

Despite differences in criteria used to define traumatic brain injury (TBI), most incident rates (hospitalised and fatal) were in the range of 150-300 per 100,000, with an overall average incident rate of 235/100,000 (Tagliaferri et al., 2006). The prevalence rate of TBI in the general population includes not just new diagnoses, but the total number of people with TBI in the population at any one time, including those with TBI sequelae such as impairment, activity limitation and restriction of participation. Few studies internationally have attempted to document the level of TBI and its consequences in the community, and there is little consistency in terms of definition of severity and duration of distribution. One Danish study (Engberg, 1995) conservatively estimated the population prevalence at 317/100,000 (only those precluded from working were included). However, a more realistic estimate from the US (Langlois, Rutland-Brown, Thomas, 2004) which includes related impairment and disability, is 1893/100,000 (approximately 2 per cent), and from the UK, among working adults under 65, is 1200/100,000 (Department of Health UK, 2005). If these estimates are applied to the Irish population, there are 34,890 people of working age and 80,000 individuals in the general population living with TBI related impairment or disability (Table 1.3). However, this is likely to be a significant underestimation of the true prevalence.

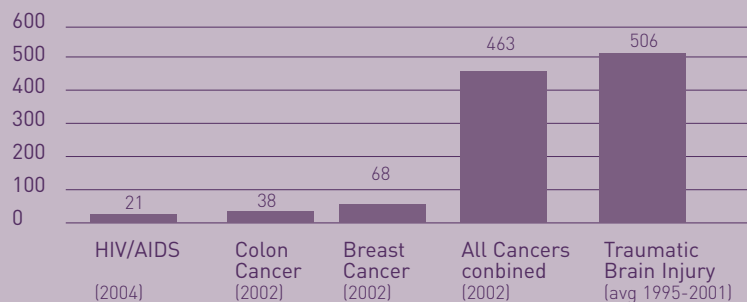
**Table 1.3** Estimated incidence and prevalence of ABI in Ireland

Acquired Brain Injury	Incident rate /100,000	Prevalence /100,000	Prevalence applied to 2006 Irish Census Data	95% Confidence Interval on Prevalence
<b>Traumatic Brain Injury</b>				
General Population (N=4,239,848)	235 (range 150-300)	1893(US)	80,260	76,679 - 83,842
Age 15-65 (N=2,907,473)	1.2-2.7	1200(UK)	34,890	32,927 - 36,852
<b>Cerebrovascular events</b>				
General Population (N=4,239,848)	205	100	4,240	3,409 - 5,070
Over 55 (N=87,4981)	420-620	500	4,375	3,992 - 4,757
Brain Tumour	16.4	131	5,554	4,604 - 6505

**SOURCE:** Barbara O'Connell, Acquired Brain Injury Ireland. (Individual references for this information are listed at the end of the chapter)

#### International Data

**Fig 1.1** Incidence of select health problems in the US - incidence per every 100.000 people



**Source adapted from:** Centers for disease control and prevention (CDC), 2006. Incidence of select health problems in the US. Atlanta: CDC.

There are currently at least 127,894 people living with the sequelae (a condition which is the consequence of a previous disease or injury) of ABI in Ireland today. ABI results in physical, communicative, behavioural, emotional and cognitive problems, which can affect every aspect of the individual's and his or her family's lives.

There needs to be some established mechanism whereby all individuals with symptomatic ABI can access the services they need as and when they need it. As neurological recovery following ABI takes place over an extended period of many months or years, fundamental to rehabilitation services is the appreciation that different patients need different input at different stages in their recovery.

#### **British Society of Rehabilitation Medicine (2004) best practice guidelines recommend that:**

- people with ABI have access to specialist services;
- there is a clear rehabilitation pathway with a continuum of care;
- people with ABI may require different services at different times;
- people with ABI may require multiple services;
- specialist support for the family is an essential component of rehabilitation;
- services should be co-ordinated and integrated;
- people should have access to lifelong support if needed.

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## PART I THE CHALLENGE

**Chapter 2:** The need for a specific response to neurological conditions in the Irish health service

The Neurological Alliance of Ireland

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“When I wake up in the morning, I wonder what day of the week it is and I can never remember. I have been constantly advised to keep a diary and I keep on saying that I am afraid that I will lose it; I am afraid that someone will find out all about me if they find it. Some of the things that I would find in the diary, I could not recall at all, and it would make me feel very worried that I really did not know myself very much at all, and make me go inside myself and avoid talking to anybody. I like to go to the cinema, but after I come out I can’t remember what the film was all about. I have learned to live with this, to simply enjoy the moment I’m living, without worrying about remembering or not.”

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## **Chapter 2 – The need for a specific response to neurological conditions in the Irish health service The Neurological Alliance of Ireland**

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### **Introduction**

People with neurological conditions are common presenters to health care; they are estimated to account for one in five visits to A&E, and one in eight visits to a general practitioner (Association of British Neurologists, 2003). It is important that health services are designed to promptly recognise and treat people with these serious conditions, whereas delays and inappropriate care can lead to loss of function and disability with lifelong consequences for individuals and their families. Failure to manage neurological conditions appropriately at the early stages has implications for long-term demands on the health system, including frequent presentations to A&E, lengthy hospital stays and longer periods of specialist and community rehabilitation.

“There is evidence that people with long-term neurological conditions have improved health outcomes and better quality of life when they are able to access prompt specialist expertise to obtain a diagnosis and begin treatment.” (Department of Health UK, 2005)

Surveys of people living with neurological conditions find that they report a range of difficulties in accessing services around the care and treatment of their condition. This chapter will concentrate on the experiences of people with neurological conditions in Ireland, as well as examining the Irish response to date in identifying and meeting the needs of these individuals within the health system.

(Note: While this chapter will address the health care needs of people with neurological conditions as a group, it is not intended to reflect the full range of services and supports required by individuals with specific neurological conditions. A number of comprehensive reports and guidelines on the management of individual neurological conditions are available and should be consulted for further reference.)

### **The challenge of meeting the needs of people with neurological conditions within a health service**

Meeting the needs of people with neurological conditions represents a unique set of challenges for the health services:

#### **These include:**

- the long-term nature of many neurological conditions, resulting in changing needs over time as the individual ages and/or the condition progresses;
- the rapidly progressing nature of some neurological conditions, with treatment care and equipment needing to be provided quickly in response to increasing disability;
- transition across different health care settings. The initial onset or the diagnosis of a neurological condition is typically managed within an acute hospital setting with the individual discharged to a community setting, often in a different geographical location;
- complex sequelae of neurological conditions including physical or motor problems, sensory problems, cognitive or behavioural problems, communication problems and psychosocial and emotional effects of the condition. Managing these consequences requires the input of a large number of different health professionals. It is estimated that a person with a neurological condition may see up to 30 different health professionals and agencies involved in their care;
- the limited number of specialist personnel involved in the management of neurological conditions. These are concentrated in specialist centres with the challenge of making this expertise and information available to staff working in a range of non-specialist health care settings.

### **What is the experience of people with neurological conditions in accessing health services?**

The Neurological Alliance UK survey, In Search for a Service (2001), questioned people living with a range of neurological conditions, as well as relevant support organisations, to examine their experiences in accessing services for the management of their condition.

Among a range of findings, the survey noted that respondents reported a number of difficulties in accessing care and treatment for their condition including:

- problems accessing specialist neurological services, resulting in long waiting lists for diagnosis and follow-up appointments;
- difficulties accessing appropriate rehabilitation services such as neurophysiotherapy, speech and language therapy, domiciliary care, neuropsychiatry and special continence care;

- concern over appropriate residential care with staff not trained in dealing with their condition;
- issues for people with neurological conditions in getting information about their condition, including how and when the information is communicated.

### **An insight into the experiences of people with neurological conditions in Ireland: The Neurological Alliance of Ireland (NAI) mapping project**

Reports on specific neurological conditions and feedback from individual service users and support organisations suggest that people with neurological conditions in Ireland have significant difficulty in accessing services to meet their needs.

In 2008, the NAI designed a project to examine these experiences through mapping the typical service journey of a person with a specific neurological condition. Member organisations of the NAI, representing a wide range of different neurological conditions, took part in the project. They were requested to represent, either through a diagram or through description, the following:

- the different stages of the neurological condition, e.g. acute onset/diagnosis, post acute etc.;
- the services people come into contact with at each stage;
- gaps in services identified at each stage;
- any key transition points in the service journey, e.g. transition from paediatric to adult services or from hospital to community which must be carefully managed to ensure co-ordination of care;
- key stages in the pathway where people are at risk of receiving inappropriate care to meet their needs.

The project provided a valuable insight into the typical service journey of people with neurological conditions in Ireland.

There are three fundamental lessons that can be summarised from this project:

#### ***1. Early and appropriate intervention is critical***

A clear effect was reported of delayed diagnosis and access to appropriate treatment on people with neurological conditions in Ireland in terms of increased disability and need for more intensive long-term support at later stages of the condition.

#### ***2. Integrated care pathways would significantly improve service journeys***

It was a frequent finding that people experience inappropriate care due to a lack of understanding of their needs. Guidelines and protocols for the management of specific neurological conditions are required to allow staff in a range of general health care settings to identify and respond to the needs of people with neurological conditions. There is a need to co-ordinate the delivery of services through a single point such as key worker or case manager. This is due to the fact that the course of delivery of care will see the involvement of multiple health professionals and agencies, a change in the needs of the individual over time, and delivery of care in different health settings with varying levels of expertise and experience in managing neurological conditions.

#### ***3. Appropriate service journeys require appropriate services***

People with neurological conditions require access to a range of specialist services and expertise at each stage of their condition. There is a significant dearth of these services across the country, and in the capacity of existing services to meet the level of need.

### **Meeting the needs of people with neurological conditions in Ireland: The NAI Standards of Care**

The Standards of Care documents (NAI, 1999- 2002) were published in three volumes, and made a series of detailed recommendations in relation to living with neurological conditions in Ireland. They represented a pioneering initiative to increase understanding of the issues involved in the care of people with neurological conditions across all areas of the health service. While it was recognised that each neurological condition represents a unique set of needs and experiences, it was noted that some could be grouped according to common issues and challenges for the individuals living with these conditions and their families:

**Vol 1: People with disabling (progressive and static) neurological conditions;**

**Vol 2: People with non-physically-disabling neurological conditions;**

**Vol 3: People with disabling neurological conditions where cognitive decline is a major feature.**

Note: The following section can only present the briefest summary of the main recommendations of each of the standards documents. This summary is not intended to cover the depth of comprehensive treatment contained in the documents themselves, which should be read in full.

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### Vol 1: Disabling neurological conditions

The first in the Standards of Care series addressed the needs of people with disabling static or progressive neurological conditions. Progressive neurological conditions are characterised by an increasing deterioration in neurological function over time, leading to increasing disability and dependence on others. In some conditions, such as motor neurone disease, this deterioration may take place over a period of months while in other conditions it may take years. Progressive neurological conditions include motor neurone disease, multiple sclerosis, Parkinson's disease and Alzheimer's disease.

Static conditions may become medically stable after a period of sudden onset, but the needs of the person change over time. These conditions include spinal cord injury, stroke and acquired brain injury.

**Some of the needs of people with disabling neurological conditions can be summarised as follows:**

- prompt referral to an appropriate specialist for diagnosis and treatment, with provision of information about the relevant support organisation at the time of diagnosis;
- services need to be designed to respond quickly and appropriately to changes in the needs of an individual due to the progression of their condition or life circumstances;
- there is a critical need for one person to be responsible for co-ordinating care;
- people with increasingly disabling neurological conditions need to be provided with appropriate choices around residential care, home support and respite depending on their needs and wishes.

### Vol 2: Non-physically-disabling neurological conditions

These include conditions such as epilepsy, headache or migraine and acquired brain injuries where the person may not have an obvious physical disability but may experience a range of intellectual, psychological and behavioural consequences as a result of their condition.

**Some of the needs of people with non-physically-disabling neurological conditions can be summarised as follows:**

- need for access to specialist services for the diagnosis, rehabilitation and long-term management of these conditions;
- need for frequent specialist review to take advantage of new treatments and approaches;
- need for one person to be responsible for the delivery of care given the long-term nature of these conditions, characterised by transition from hospital to community settings and changing needs over time.

[Note: Acquired brain injury represents a unique set of experiences for the individual and requirements for specialist services. Comprehensive information on this area should be sought from the range of publications available and relevant support organisations].

### Vol 3: Disabling neurological conditions where cognitive decline is a major feature

This category includes conditions such as Alzheimer's disease and other causes of dementia, Huntington's disease and acquired brain injuries where there are intellectual changes as a result of the condition.

**some of the needs of people with disabling neurological conditions where cognitive decline is a major feature can be summarised as follows:**

- a clear diagnosis should be made as soon as possible to reduce the period of anxiety for the person and their family, and this diagnosis should be communicated sensitively in an appropriate setting and with information provided on the condition and relevant support organisations;
- the availability of specialist teams around these conditions to liaise with a range of health care staff in different settings to make sure the needs of these individuals are appropriately identified and responded to;
- need for appropriate long-term care, respite and home support services.

**Each of the Standards of Care documents recognises:**

- the need for the individual with a neurological condition to be consulted in the planning and delivery of their care;
- the role of family carers in managing the neurological condition and their need for appropriate training, support and information.

### **Meeting the needs of people with neurological conditions in the Irish health system: the response to date**

There have been a number of responses to identifying and meeting the needs of people with neurological conditions in the Irish health system. The NAI Standards of Care outlined in the previous section were instrumental in promoting recognition of the unique requirements of these individuals within our health services. This led directly to the commissioning of a report by Comhairle na nOspidéal (2003) into service provision in neurology and neurophysiology in Ireland. The report made a series of recommendations including the need to significantly increase the number of consultant neurologists, to develop multidisciplinary teams and to provide regional services and outreach clinics to address long journey times to national centres. The report also outlined the lack of adequate provision for specialist neurorehabilitation in this country, recognising the increased pressure this places on acute neurology services. It stressed the need for a strategic review in this area.

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Neurosurgery services were addressed in a 2006 report by Comhairle na nOspidéal, which recommended increasing the number of consultant neurosurgeons and neurosurgical multidisciplinary teams and providing appropriate settings and equipment, as well as improved transport to neurosurgery centres. This report also recognised the critical importance of a network of specialist neurorehabilitation services to ensure appropriate care and treatment and promote timely discharge from acute neurosurgery centres and again stressed the importance of a national review of neurorehabilitation service provision.

Following a number of meetings with the NAI and other stakeholders, the Health Service Executive (HSE) moved to address the slow progress in implementing the recommendations of the Comhairle na nOspidéal reports and the need for a strategic approach to the management of neurological conditions within the health services. The Strategic Review of Neurology and Neurophysiology Services (2007) represents the culmination of an intensive in-depth body of work by all stakeholders, including NAI member organisations. The Laffoy report (so termed because it was authored by Dr Marie Laffoy, then National Director of Population Health, HSE) provides a comprehensive blueprint for the development of services for people with neurological conditions in Ireland by addressing the following critical issues:

- the need for the development of multidisciplinary, acute neurology services to allow for the prompt diagnosis and treatment of neurological conditions;
- the need to develop a network of community based services to liaise with acute neurology to provide for the ongoing long-term needs of people with neurological conditions;
- the recognition of the important role of non-statutory organisations in providing services and supports for people with neurological conditions;
- the need for the development of the neurosciences in Ireland through promoting research, academic development and training and access to new treatments.

Importantly, the Laffoy report recognises the need for an overall strategic vision for neurological care within our health service. Specific strategies in the area of stroke and neurorehabilitation should form part of an overall focus to prioritise the development of services for people with neurological conditions in this country.

The development of the National Neurorehabilitation Strategy (still to be published at the time of writing) presents a significant opportunity to address policy and service provision in this critical area of neurological care.

## **Opportunities for improving neurological care within our health services**

Two examples are selected below to illustrate the capacity of current health service reform to improve the delivery of neurological care in Ireland:

### ***1. The Primary Care Strategy***

There is a vital need to develop a clear vision for the role of the primary care team in the management of neurological conditions. The potential value in co-ordinating the work of a range of local health care providers must include a consideration of their access to specialist expertise for the diagnosis, ongoing care and rehabilitation of people with neurological conditions.

### ***2. Development of clinical pathways for specific neurological conditions: the Office of the National Director of Quality and Clinical Care***

The Quality and Clinical Care Directorate, recently established by the HSE, will introduce a series of changes and improvements to the way in which health services are delivered in order to promote:

- Simplified patient journeys
- Easier access to primary and community care
- Easier access to hospital services where needed
- More chronic illness programmes to enable people to be cared for outside hospitals
- More transparent and measurable standards
- Greater staff involvement in transformation

(Source, Dr David Vaughan, Office of the National Director of Quality and Clinical Care, HSE in a presentation to the Neurological Alliance of Ireland, March 2010)

The introduction of uniform clinical standards and approaches to the management of neurological conditions has significant potential to improve the quality of neurological care in Ireland. As the umbrella body representing the needs of people with neurological conditions, the NAI wish to emphasise the following in relation to the work of Quality and Clinical Care Directorate:

- As well as improving access to hospital based services for the diagnosis and treatment of neurological conditions, clinical pathways must address the significant gaps in community based services for the rehabilitation and long term management of these conditions;

- Clinical pathways need to include mechanisms for referral and guidelines for the long-term management of neurological conditions to ensure continuity of care across all stages of the condition;
- The development of clinical pathways for neurological conditions must take into account the training and information needs of those working across all areas of the health service in relation to the care and treatment of people with these conditions;
- The Neurological Alliance of Ireland pioneered the identification of the key requirements for neurological care in this country through the Standards of Care documents. Clinical directors need to recognise the experience and expertise of non statutory organisations and work in partnership with NAI member groups in order to ensure that people with neurological conditions receive the range of services and supports they require.

**Integrated Clinical Pathways for Neurological Conditions:** An opportunity for our health service to deliver quality in neurological care.

Dr David Vaughan  
Office of the National Director of Quality and Clinical Care  
Health Services Executive

The recent and ongoing economic downturn has forced governments and healthcare agencies around the world to confront the ever-increasing costs of healthcare. Such a crisis has brought both hazards and indeed opportunities. It is clear now that the ever-increasing cycle of investment in healthcare demand cannot continue without a radical reform of healthcare supply. It is widely acknowledged that during times of plenty, neurological services did not receive its due in terms of service development. Lack of investment in the last two decades has had profound implications for patients and families coping with chronic neurological illness in Ireland.

However, despite the lean economic environment we believe that neurological services (including neurological surgery and rehabilitation) have the capacity to act as a paradigm for the principle of healthcare reform in the creation of a patient centred, responsive, flexible, and high quality service. We are aware of the many innovative programmes that neurological services have introduced in the last number of years. The quality of submissions for the 2010 NAI innovation award is testament to that.

From the point of view of the Office of National Director of Clinical and Quality Care, our priority is to engage with clinicians first and foremost, to develop appropriate national guidelines for quality care and to stimulate the development of the infrastructural arrangements in terms of staff, space and information technology required to deliver an integrated care pathway for all of the major neurological illnesses. We wish the NAI, which as an umbrella organisation for the voluntary sector will be an important part of the solution, the best of luck in the dissemination of this important document which embodies in our view an appropriate vision for change.

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## **Conclusion: The need for a strategic focus on neurological care in Ireland**

The NAI is concerned that, despite the endorsement of its recommendations by two external consultant neurologists engaged by the HSE in 2009, the Strategic Review of Neurology and Neurophysiology Services has not been published to date. Given the recent development of the National Neurorehabilitation Strategy, there is a unique opportunity at the present time to implement the recommendations contained in both of these documents, to provide a framework for our health services in order to respond to the needs of people with neurological conditions.

We recognise that a proper framework for neurological care in Ireland will require changes and improvements in the way in which services are delivered in order to ensure the best outcomes for service users and to enhance the capacity of all areas of the health service to meet the requirements of individuals with neurological conditions.

There is an increasing requirement for an ongoing consultative mechanism to ensure that our health system is informed and responsive to the needs of people with neurological conditions. Mental health services, palliative care, respite care and a range of other services need guidelines on supporting these individuals and their families. The Neurological Alliance of Ireland, as the representative umbrella for organisations supporting people with neurological conditions, continues to play a key role in this regard. The critical need to improve the provision of care to people with neurological conditions in Ireland is constrained by the continued absence of a specific focus on this area of healthcare to date. The NAI Standards of Care documents outlined the requirement for an integrated response to the needs of individuals with neurological conditions and their families across all areas of health service provision. Since then, while limited investment and improvements in service delivery have taken place, there is no strategic direction available to guide the development of neurological care in this country. Ensuring that people with neurological conditions in Ireland receive the quality of care they need and deserve will require continuing investment in specialist services and personnel, as well as changes in the way services are delivered to ensure that resources are used to best effect and examples of best practice and innovation can be rolled out on a nationwide basis. Two examples provided at the end of this chapter outline how other jurisdictions have identified and responded to the needs of people with neurological conditions within their health services through the development of national strategic frameworks involving quality standards for neurological health services and specific targets and guidelines for optimum care and management of neurological conditions. Ireland continues to lag behind all other European countries in this area.

### **In summary, the NAI is calling for a strategic focus on neurological care within our health service, which will require:**

- the need to implement the existing recommendations in this area, including the Strategic Review of Neurology and Neurophysiology Services and the National Neurorehabilitation Strategy, to create a network of neurospecialist services and personnel which can respond to current and future demand;
- the need to change and improve the way in which services are delivered in order to address the range of needs of the person with a neurological condition across all areas where they come into contact with the health services;
- a clear commitment to prioritising neurological care in Ireland through target setting and year on year development plans based on a recognition of the continuing unmet need in this area and emerging demographic trends;
- the need to support and strengthen the role of the NAI of Ireland as a partner in the development of policy and practice in neurological care.

## **Integrated responses to meeting the needs of people with neurological conditions: lessons from other health systems**

Examples are taken from the UK Department of Health National Service Framework (2005) for neurological conditions and the standards for neurological health services developed by NHS Quality Scotland (2009). These initiatives highlight the importance of providing a national direction for neurological care, to ensure a uniform response to meeting the needs of people with neurological conditions across all areas of health service provision.

### ***1. The UK National Service Framework for long-term (neurological) conditions***

The UK Department of Health (2005) has developed a set of quality requirements for services for people with long-term neurological conditions based on detailed consultation with service users and service providers. The aim of these guidelines is to bring about a structured and systematic approach to delivering treatment and care for people with neurological conditions and their families across all stages of the patient journey. A summary of the quality requirements is provided below. Those involved in the planning or delivery of services for people with neurological conditions should consult the full report for a more comprehensive explanation of the guidelines, including evidence-based markers of good practice for service providers.

### **Quality requirements: National Service Framework (NSF) for long-term (neurological) conditions**

#### **Quality requirement 1: A person centred service**

People with long-term neurological conditions are offered integrated assessment and planning of their health and social care needs. They are to have the information they need to make informed decisions about their care and treatment and, where appropriate, to support them to manage their condition themselves.

#### **Quality requirement 2: Early recognition, prompt diagnosis and treatment**

People suspected of having a neurological condition are to have prompt access to specialist neurological expertise for an accurate diagnosis and treatment as close to home as possible.

#### **Quality requirement 3: Emergency and acute management**

People needing hospital admission for a neurosurgical or neurological emergency are to be assessed and treated in a timely manner by teams with the appropriate neurological and resuscitation skills and facilities.

#### **Quality requirement 4: Early and specialist rehabilitation**

People with long-term neurological conditions who would benefit from rehabilitation are to receive timely, ongoing, high quality rehabilitation services in hospital or other specialist settings to meet their continuing and changing needs. When ready, they are to receive the help they need to return home for ongoing community rehabilitation and support.

#### **Quality requirement 5: Community rehabilitation and support**

People with long-term neurological conditions living at home are to have ongoing access to a comprehensive range of rehabilitation, advice and support to meet their continuing and changing needs, increase their independence and autonomy and help them to live as they wish.

#### **Quality requirement 6: Vocational rehabilitation**

People with long-term neurological conditions are to have access to appropriate vocational assessment, rehabilitation and ongoing support, to enable them to find, regain or remain in work and access other occupational and educational opportunities.

#### **Quality requirement 7: Providing equipment and accommodation**

People with long-term neurological conditions are to receive timely, appropriate assistive technology or equipment and adaptations to accommodation to support them to live independently, help them with their care, and maintain their health and improve their quality of life.



**Quality requirement 8: Providing personal care and support**

Health and social care services work together to provide care and support to enable people with long-term neurological conditions to achieve maximum choice about living independently at home.

**Quality requirement 9: Palliative care**

People in the later stages of long-term neurological conditions are to receive a comprehensive range of palliative care services when they need them to control symptoms, offer pain relief, and meet their needs for personal, social, psychological and spiritual support, in line with the principles of palliative care.

**Quality requirement 10: Supporting family and carers**

Carers of people with long-term neurological conditions are to have access to appropriate support and services that recognise their needs both in their role as carer and in their own right.

**Quality requirement 11: Caring for people with neurological conditions in hospital or other health and social care settings**

People with long-term neurological conditions are to have their specific neurological needs met while receiving treatment or care for other reasons in any health or social care setting.

Source: Department of Health UK, 2005. National Service Framework for long-term neurological conditions. London: Department of Health UK.

**2. Clinical Standards for Neurological Health Services: Scotland**

A set of clinical standards for neurological services have recently been developed by NHS Quality Improvement Scotland (2009). A set of generic standards apply to all neurological health services (with the exclusion of paediatric neurological health services and those for acquired brain injury and stroke). In addition, condition specific standards are provided for five common neurological conditions (epilepsy, headache, motor neurone disease, multiple sclerosis and Parkinson's disease). These conditions were selected as they represent a high proportion of all neurological chronic conditions managed in both primary and secondary care.

Both the NSF and the Scottish standards present important comparisons for our own health services. They represent a co-ordinated approach to meeting the needs of people with neurological conditions across all areas of health service provision, from diagnosis or onset to early management through to long-term care needs. Through the development of standards and quality requirements, there is a clear expectation that specialist services need to be developed and resourced to meet the requirements of the individual at each stage of their condition.

The availability of a national framework for neurological care is vital to plan and prioritise the development of services, to allow resources to be directed to where they are most needed and to ensure that the best models of care are adopted for the management of neurological conditions.

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## PART I THE CHALLENGE

**Chapter 3:** The need to develop a network of specialist neurorehabilitation services in Ireland  
Dr Áine Carroll, Consultant in Rehabilitation Medicine, National Rehabilitation Hospital

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“I have had Complex Partial Seizures all of my life and they were never fully controlled on anti-epileptic medications. I found it hard to concentrate in school and I also found it hard to be made permanent in a job. When I had a seizure I would usually go into a trance. I wouldn't be able to talk properly and wouldn't comprehend what was being said to me during a seizure.

When I was 25 I made a decision to go ahead and be tested as a candidate for surgery. I had surgery in January 2007 and I have been seizure-free since. I am still on medications but the doses have been reduced. I am now holding a full time permanent job, learning to drive and I am doing well.

I haven't had any difficulty in accessing health services as I am a private patient and I have been so all of my life so I was able to access neurologists a lot quicker than a public patient can.

I think there should definitely be more neurologists and neurosurgeons in Ireland. At the moment there aren't enough to deal with the population and it can take anything from a year to two years for patients to get an appointment with neurologists.”

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## **Chapter 3 - The need to develop a network of specialist neurorehabilitation services in Ireland**

### **Dr Áine Carroll, Consultant in Rehabilitation Medicine, National Rehabilitation Hospital**

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#### **Introduction**

The World Health Organisation (WHO, 2001) defines rehabilitation as “an active process by which those affected by injury or disease achieve a full recovery or, if a full recovery is not possible, realise their optimal physical, mental and social potential and are integrated into their most appropriate environment”.

Rehabilitation services should act like a bridge between isolation and exclusion. Rehabilitation following injury or disease is a basic human right, which is supported by the United Nations Charter through its 1993 standards document and by the European Year of People with Disabilities, 2003, and should start as soon as possible after the diagnosis of a neurological disorder or condition. The type and provision of services is largely dependent on the individual health care system, however, individuals requiring services should have access to rehabilitation in a timely manner and across the continuum of care from acute and post acute care to community and sustaining services.

#### **Stages in the rehabilitation process**

Individuals requiring rehabilitation have different needs at different times and any system must be able to respond to such changing needs. There are four stages to the rehabilitation process:

##### **1) Acute rehabilitation**

Following the onset of an acute illness or injury, an individual often requires acute hospital care for a few weeks. Rehabilitation should start as soon as possible and focus on nursing care and therapy to reduce the complications of immobility, confusion, problems with swallowing and breathing and learned behaviour. Early rehabilitation reduces the risk of developing preventable secondary complications and reduces length of stay in hospital and re-admission rates.

##### **2) Post-acute inpatient rehabilitation**

Specialist rehabilitation comes into its own in the post-acute stage as the patient starts to recover and needs to make the transition between hospital and community. It focuses on regaining the skills of independent living to allow the patient to manage at home.

##### **3) Community rehabilitation**

Once back at home, patients need continued input to maximise their ability to function in their environment. Depending on the individual's goals this may require ongoing treatment in day or outpatient services or may be more appropriately undertaken in the patient's own familiar surroundings by an outreach team or by community therapy.

##### **4) Continued support for disabled individuals and their families**

In the long term, most patients will not require continuous rehabilitation, but may need access to sustaining services such as drop-in clinics or access to services or information by self-referral.

#### **What is a specialised rehabilitation service?**

A specialised rehabilitation service may be broadly defined as “a service for patients with severe complex disabilities whose rehabilitation needs are beyond the scope of their local rehabilitation services”. Complex specialised rehabilitation services are high-cost and low-volume. They provide services to those with complex physical, communicative, cognitive and/or behavioural disabilities as a result of injury or illness. The most common cause of such deficits is acquired brain injury, but there are many other causes of complex disability, which will require access to such services.

According to international standards, a specialist rehabilitation service provides total active care of patients with complex disabilities, and their families, and consists of a multidisciplinary team, which includes a consultant specialist in rehabilitation medicine. The Royal College of Physicians UK Blue Report (1986) makes the clear recommendation that every district, with a population of 250,000, should have such a service (Royal College of Physicians, 1986). That document also recognised that for certain uncommon complex conditions such as severe brain injury, which requires highly specialised skills and facilities, it was both more practical and more cost-effective to provide services to a supra-regional catchment (1-3 million population).

## Benefits of specialist inpatient neurorehabilitation

There is now a substantial body of evidence that confirms that rehabilitation in specialised settings for people with traumatic brain or spinal cord injury is effective and provides value for money in terms of reducing the length of stay in hospital and reducing the costs of long-term care (Cope and Hall, 1986; Turner-Stokes, 2004; Cardenas et al., 2001; Nyein et al., 1999).

Evidence has shown that early transfer to specialist centres (Cope and Hall, 1986; Turner-Stokes, 2004) and more intense rehabilitation programmes (Klauber et al., 1989; O'Sullivan et al., 1990; Rockswold, 1987) are cost effective. The latter is particularly so in the small group of people who have high care costs due to very severe brain injury (Ashkan, 2001; Aung and el Masri, 1997; Department of Health UK, 2002; el Masri, 2003; Smith, 2002; Turner-Stokes and Wade, 2004). Providing adequate, properly staffed and resourced neurorehabilitation services can help prevent secondary complications, which bring further health problems and increased length of stay in hospital (Wheeler et al., 1997).

## Effective specialist inpatient neurorehabilitation

Specialist inpatient neurorehabilitation services form a vital link with both acute hospital care and the community, as they can support staff to deliver early rehabilitation in the acute setting before transferring the person to the specialist inpatient unit. They also provide programmes after a period of inpatient neurorehabilitation to support transition back into the community through co-ordinated care planning in close collaboration with providers of community rehabilitation and support (Department of Health UK, 2005).

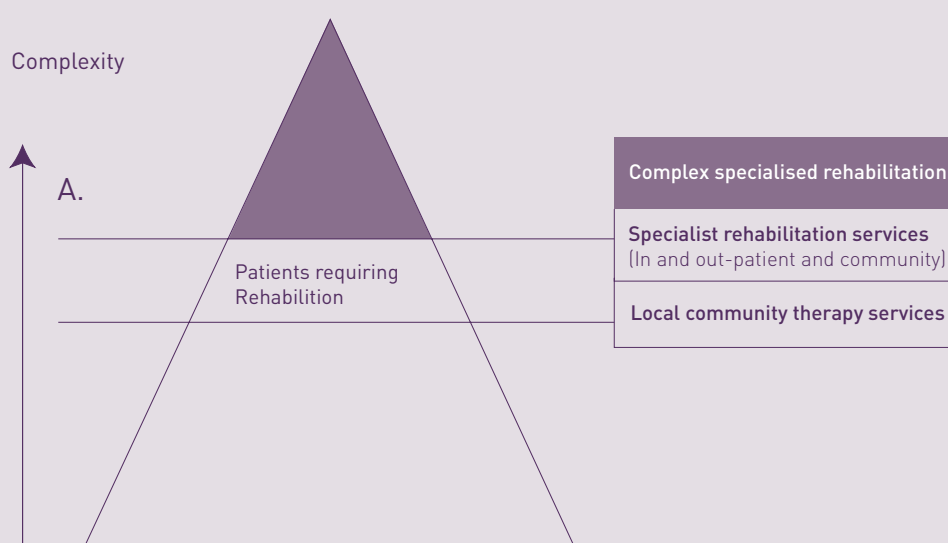
People with complex health care needs may require continued access to specialist neurorehabilitation as their needs change. Planned re-admissions to the inpatient unit over a number of years may be the most appropriate way of meeting their changing needs. Those who have additional health conditions may also need to access specialist neurorehabilitation, and special arrangements may be necessary to meet their full range of needs (e.g. renal dialysis).

A few people with very severe and complex disabilities (e.g. those in persistent vegetative or low-awareness states, or with severe cognitive or behavioural problems) may need highly specialised and structured service provision over a prolonged period. Such highly specialised inpatient facilities are likely to have national status (Department of Health UK, 2005).

## Complex specialised rehabilitation services

With access to appropriate services, most people with mild to moderate disability may be managed in a local setting through local services. A minority, however, will have particularly severe or complex problems and require the services of a complex specialised rehabilitation service to progress (Figure 1.2).

Figure 1.2: The different levels of rehabilitation service provision (the top tier above A denotes specialised service)



Source: Adapted from Department of Health UK, 2009. Specialised Services National Definitions Set (2nd ed.). London: Department of Health UK.

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## The characteristics of complex specialised rehabilitation services

As complex specialised rehabilitation services usually involve an intensive treatment programme, and individuals are usually in need of a significant amount of care, this is usually provided through inpatient services (Nyein et al., 2007; Turner-Stokes, 2007). However, not all individuals will require inpatient services and will need to avail of day and outreach services to provide follow-up rehabilitation and support. The bedrock of complex specialised rehabilitation services is co-ordinated interdisciplinary team-working, provided by a team of therapists, nurses and doctors with specialist training and accreditation in rehabilitation. Co-ordination is achieved by integrated multidisciplinary activities e.g. interdisciplinary health care record, ward rounds, case conferences, discharge planning, etc. Frequently, it involves joint therapy sessions to address specific tasks.

Patients with complex needs usually require intensive therapeutic input, usually for several hours a day and may require two or more therapists at a time. Specialist programmes are of significant duration depending on the goals for rehabilitation and the individual needs of the patient, but may last several months.

Patients requiring specialist services have complex care requirements in terms of nursing dependency levels and/or physical, communicative, cognitive and/or behavioural problems. Many patients require continued support or are unable to return to their own homes because of care or environmental factors, so co-ordinated discharge planning involving health, social services and often employment or education authorities is required.

Complex specialised rehabilitation services offer a range of equipment and facilities not available in more general services and therefore may act as demonstration centres for assessment of suitability for prescription, e.g. of electro-assistive devices, special seating systems, specialist orthotics, etc.

In general, complex specialised rehabilitation services offer services that meet the standards of specialist inpatient rehabilitation services as laid down by the British Society of Rehabilitation Medicine. In addition, they may offer some or all of the following specific inter-disciplinary procedures as part of their service (British Society of Rehabilitation Medicine, 2003, 2009; Specialised Services National Definition Set, 2009):

- behavioural, cognitive or neuropsychology rehabilitation programmes – either for ‘walking-wounded’, brain injured patients or those with complex behavioural syndromes in association with physical disability;
- coma-arousal programmes – for patients in vegetative or minimally responsive states;
- spasticity management – multidisciplinary programmes for spasticity management including intrathecal baclofen pumps, botulinum toxin in conjunction with serial splinting, orthotic management or postural management programmes;
- tracheo-pharyngeal management – tracheostomy weaning together with dysphagia assessment (video-fluoroscopy, etc.);
- electro-assistive technology, communication aids or computers in disability – application of state-of-the-art technology for improved independence and quality of life;
- back-to-work programmes – vocational and social rehabilitation in the light of complex physical and sensory disabilities, work assessments, employer negotiations, financial counselling, etc.
- sexual counselling – for people with disabilities and their partners;
- inpatient complex rehabilitation assessment for physical and complex disabilities;
- cognitive behavioural therapy programmes – for chronic pain syndromes, chronic fatigue, conversion or ‘enhanced disability behaviour’ states;
- treatment of patients under sections of the Mental Health Act;
- formalised family support to educate, advise, and facilitate family or carer function in the context of the patient’s immediate and long-term dependency;
- group therapy programmes – one advantage of a central unit is the opportunity to convene groups of patients with a common problem. Group sessions allow patients to gain not only from therapy but from the experience of engaging with others who have similar problems. Group programmes may include: social interaction, extended activities of daily living, awareness of current affairs, high level communication skills, work skills, etc.

## Development of rehabilitation services to date

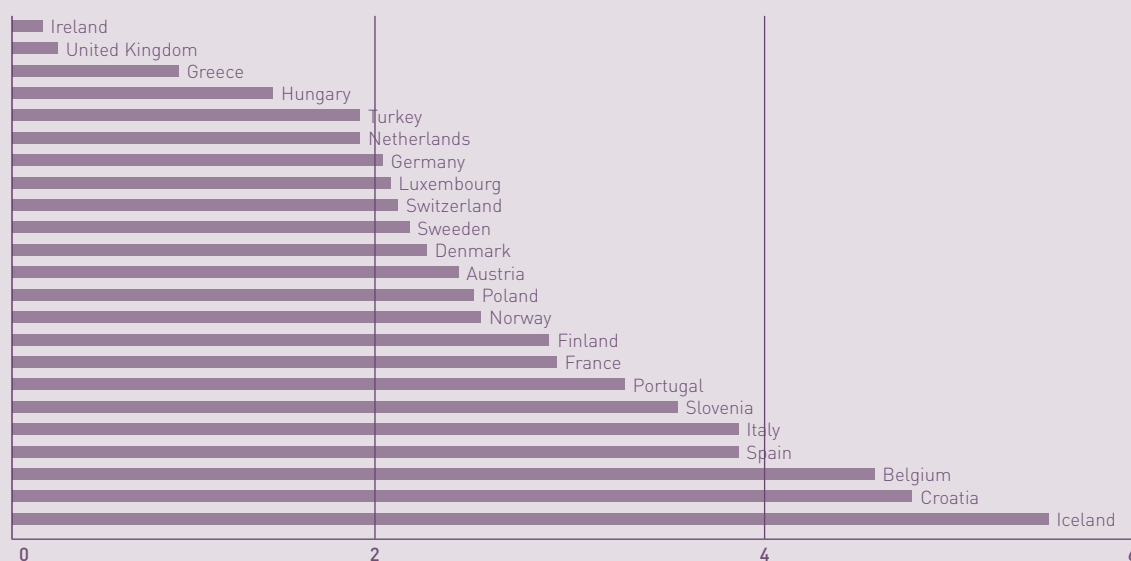
Compared with most other countries, rehabilitation services in Ireland have suffered from years of under resourcing and lack of recognition. In 1999, the Royal College of Surgeons of England’s Working Party Report on brain injury advised that “patients in neurosciences units requiring further rehabilitation should be transferred directly to a rehabilitation unit and not to a general surgical or medical unit while awaiting a bed”.

It also added: “It is unacceptable for patients to spend prolonged periods on acute surgical or medical wards while awaiting a place at a dedicated rehabilitation unit. However, should there be any delay in transferring patients to a suitable unit, rehabilitationists and neuropsychologists should become involved in their management whilst they

are still in the acute bed and prior to this discharge ... The authors hope the general thrust of their recommendations will be both acceptable to and implemented in the Republic of Ireland (Royal College of Surgeons of England, 1999; Farling, 2003)." To date, none of these objectives have been achieved.

In Ireland, the National Rehabilitation Hospital (NRH) has 121 beds and six consultant specialists in rehabilitation medicine. In a recent survey of rehabilitation consultants in the UK, there is a perceived need for six rehabilitation beds per 100,000 population with 0.4 consultants per 100,000 population (Andrews and Turner-Stokes, 2005). This equates to a recommendation for 254 post acute rehabilitation beds and 16 rehabilitation consultants for Ireland to serve the current population. There is currently a major shortage of rehabilitation beds and rehabilitation expertise. In Europe, there are large differences in the number of specialists, their role in the health system and their conditions of work. Figure 1.3 below shows the wide variation in numbers of rehabilitation specialists throughout Europe.

**Figure 1.3.** Number of rehabilitation specialists in Europe per 100,000 population



Source: Gutenbrunner, C; Ward, A B; Chamberlain, A, 2007. 'White book on physical and rehabilitation medicine in Europe (Rev. ed.)'. Journal of Rehabilitation Medicine. 39 (45):1-48.

## Conclusion

There is an unambiguous need throughout Ireland for specialist rehabilitation input through all the stages of rehabilitation. The current availability of rehabilitation in the post acute setting falls unacceptably short of the perceived need. There is also a glaring shortage of community rehabilitation facilities especially for those under 65 years.

Community therapists are already stretched and are unable to provide community rehabilitation for individuals with complex disabilities. Because of the shortage of services, there are serious problems accessing rehabilitation services in Ireland in a timely manner, at all stages of the rehabilitation process. These factors and others make it difficult for those with complex disabilities and their families to obtain the necessary support to allow them to participate optimally in the rehabilitation process.

Traditional medical rehabilitation environments often do not foster partnerships with persons with complex care needs or their families. Therefore, traditional approaches frequently result in a sense of disenfranchisement due to a lack of shared participation in goal development and programme design. In addition, information provided by clinicians to persons with complex disabilities and their families is often inappropriate, being either too overwhelming or too complex.

Fortunately, there are some organisations that are being given the opportunity to expand their services to bridge the community service gap. The NRH has not been able to increase its services in recent years and so the most alarming service gap is currently for the post acute patients who wait interminably for a bed in the NRH.

The development plans for a new NRH with 235 beds and a 25-bed acute neurorehabilitation unit in Beaumont are important steps in improving appropriate services but these projects are some years away from completion. There is an urgent need for immediate investment by government in post acute rehabilitation services and rehabilitation services across the spectrum of services to provide timely and equitable rehabilitation for those patients with complex disabilities and their carers or families all over Ireland.

### **The National Neurorehabilitation Strategy**

The Neurological Alliance of Ireland keenly awaits the publication of a national strategy for the provision of neurorehabilitation services, which has been developed jointly by the Department of Health and Children and the HSE. A working group of key stakeholders was brought together to consider the rehabilitation needs of people with (primarily) neurological conditions at both acute and community level. The objectives were to develop an appropriate policy framework for neurorehabilitation services along with a clear strategy for service provision and a preferred model of care. The National Neurorehabilitation Strategy will represent a blueprint for this critical aspect of neurological care in Ireland. The identification of a national clinical lead in this area in the 2010 HSE Service Plan represents a positive signal of commitment to the development of neurorehabilitation services.



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## **PART I**

### **THE CHALLENGE**

**Chapter 4** - Economic issues in the diagnosis and treatment of neurological conditions

Professor Charles Normand

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“I am an 18 year old male who has just been diagnosed with focal dystonia in both hands last August. Day to day I struggle with some of the most prevalent tasks that, before, I wouldn't have given a thought to, such as making a cup of tea or writing with a pen or pencil. As a musician, I find my condition particularly intrusive with regards to playing, and my progress and ability has been limited. I found no difficulty in accessing the health services. I attend a clinic at Beaumont Hospital regularly, and I find the service extremely commendable.”

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**Chapter 4 - Economic issues in the diagnosis and treatment of neurological conditions**  
**Prof Charles Normand, Edward Kennedy Professor of Health Policy and Management,**  
**Trinity College Dublin**

**Introduction**

Economists are concerned with efficiency in the widest senses. Since choices must be made (and not all desirable services can be provided) the key issues are choosing the most useful services and to provide services at minimum cost (subject to appropriate quality standards). Neurological conditions are, in principle, no different from many other illnesses, but in most cases they are chronic, treatable but are not fully curable. While the different neurological conditions differ greatly from each other in terms of the types of interventions that are useful, they have in common the problem that the specialist skills needed to manage them tend to be scarce, and new and useful investigations and treatments have often been adopted only slowly.

**Management of neurological conditions in the Irish health system**

**Table 1.4:** System sensitive conditions: Chronic conditions with good evidence of better outcomes from better services

Malignant neoplasm of colon, skin, breast, cervix, testis	Chronic rheumatic heart disease
Hodgkin's disease	Ischaemic heart disease
Leukaemia	Cerebrovascular disease
Diabetes mellitus	Respiratory disease
Epilepsy	Benign prostatic hyperplasia
Hypertensive disease	Congenital cardiovascular anomalies

Source: Adapted from Nolte, E and McKee, M, 2004. *Does health care save lives? Avoidable mortality revisited*. London: The Nuffield Trust.

Chronic illnesses are often poorly managed even in developed health systems (Nolte, Knai and McKee, 2008). Conditions listed in Table 1.4 are chronic illnesses that have been shown to have much better outcomes when health services are available and are well organised. Table 1.5 is a useful way of comparing the performance of health service provision. It shows that countries with well organised health service delivery (such as France) can reduce substantially the number of deaths compared to the average across developed countries. Although fully comparable data are not available for Ireland, other information suggests that Ireland performs relatively poorly in terms of outcomes from health services sensitive conditions. For example the likely survival in Ireland for a person born with cystic fibrosis is around eight years shorter than for someone born in Northern Ireland, and more than 10 years shorter than for a person born in Canada.

**Table 1.5:** Age standardised death rates from system sensitive conditions

Austria	72.90
France	62.75
Greece	72.35
Portugal	113.64
UK	87.43

Source: Adapted from Nolte, E et al., 2008. *Managing chronic conditions: Experience in eight countries, Observatory Studies Series*. Brussels: European Observatory on Health Systems and Policies.

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Epilepsy and stroke are among conditions where there is now firm evidence of the link between the quality of health care interventions and outcomes for patients (Nolte and McKee, 2004). The case for earlier and more skilled investigation of neurological conditions comes from a combination of potentially better treatment, more time to prepare to meet (often complex) needs, the scope to increase the participation of patients in planning the management of their conditions, better management of symptoms and serious events and better health for the individuals.

Economists focus on two related concepts of efficiency – the first is to provide services without unnecessary waste of resources, and the second is to use resources to meet the most important needs. Sometimes this is described as doing things right and doing the right things.

Pure waste can come either from using the wrong combinations of inputs, or by simply using more than is needed. It is easy to observe cases of the latter – rooms lying idle (while people search for suitable spaces), or staff hanging around waiting for the next job. When medicines go out of date they have to be thrown away and replaced. It is often possible to see examples of how we provide services using the wrong mix of staff or spaces. For example, studies have shown that in some chronic diseases outcomes can be at least as good when nurses take on some roles traditionally taken by doctors (Aubert et al., 1998), and some studies suggest that outcomes are better (Trento et al., 2008). What these studies cannot really do is to assess the wider effect of releasing specialist resources for the most complex cases, since they can only partially identify the effect of new services on meeting previously unmet needs. Buildings represent only a very small proportion of the overall cost of providing health care (typically less than 15 per cent and often less than this), but nevertheless the lack of suitable spaces can often constrain a sensible use of skilled staff. Single rooms in hospitals have been shown to lower costs of providing acute care than in conventional wards (Ulrich, 2009). Short term budget constraints often cause inefficient use of expensive and very scarce skills by restricting access to the necessary spaces and services.

Current provision of services for people with neurological conditions shows clear signs of inefficient combinations of staff, facilities and other inputs, and there is emerging evidence of problems in the co-ordination of primary, secondary and tertiary services in Ireland (Varley et al, in press). Further work, tracing the journey of patients through the different levels of care, reveals avoidable barriers to appropriate access to care. It also shows some problems of limited confidence to manage epilepsy in the community and some waste of scarce resources due to poor referral processes. Work on improving information through electronic records suggests that the general level of efficiency can be improved (Breen et al., 2009). Wider studies of this type of efficiency in health care provision have suggested that there is clear scope for improvements – typically of more than 15 per cent simply by replicating the performance of the most efficient systems (Erlandsen, 2008).

The more important concept of efficiency is concerned with doing the right things – that is providing those services that will have the greatest impact on health and quality of life. Formal economic evaluation of health care priorities has been carried out in some countries since the 1970s, but has as yet had relatively little effect on priority setting in Ireland. The process is, in principle, relatively simple – health care interventions are assessed in terms of the impact on health and quality of life (often using years of life gained, quality adjusted years of life gained or some measure of improved health status), and this is set against the cost of providing the services (McPake and Normand, 2008; Drummond et al., 2005). Priorities are chosen according to the ratio of benefits to costs. The processes have become increasingly sophisticated, with techniques to extrapolate long-term outcomes from short-term studies, and ways of handling risk and uncertainty, but the underlying principles are simple.

Many countries have an informal benchmark in place for what is included in publicly funded health care: the cost of maintaining a person with renal failure on dialysis (Rabinovich et al., 2007). In the United States that cost is estimated at US\$50,000 per year. If a treatment programme can be shown to provide benefits in terms of longer life (or its equivalent in improvement in the quality of life) at less than this cost, it is deemed to be cost-effective.

Economic evaluation has often shown that some programmes that manage chronic diseases have been given lower priority than is appropriate – or put another way they offer more benefits per euro spent than is the case for some treatments that are provided. There can be several reasons for this, including the fact that urgent (but not necessarily the most important) interventions get into the public debate more easily. The organisation of health care delivery often makes chronic disease management unnecessarily difficult, with the delivery systems geared mainly to episodic events, while the need is for continuity and linkage. To an extent, the problem has also been that some chronic disease services improve quality of life but not necessarily how long people live. However, there is now clear evidence that well organised services for some neurological conditions can significantly increase both life expectancy and health related quality of life (Nolte and McKee, 2004). Especially in stroke and epilepsy services the evidence shows that the relationship between service quality and outcomes is very strong. In other conditions the evidence is still emerging, but is likely to show similar patterns as the effectiveness of treatments and care services becomes clearer.

In setting priorities there are some times when the need is to support research and experimental services, since it is only through better evidence that priorities can be properly identified. Even when there is only limited scope for affecting the course of a disease, it can be important (and cost-effective) to ensure timely and accurate diagnosis, and to be in a position to plan better for the emerging patterns of care that will be needed. In some cases, there is a particular need to get an appropriate diagnosis to avoid potentially harmful treatment. For

example, where someone with an intention tremor is wrongly diagnosed and is being treated for Parkinson's disease there is both a risk of avoidable side effects and a cost in terms of ineffective drugs. While some primary care professionals are highly skilled in managing neurological diseases, there is a problem of some inappropriate prescribing and treatment strategies.

## Conclusion

It has often been argued that there is a serious shortage of specialists in neurology in Ireland, and there is clear evidence that the current services are seriously congested. This in itself can reduce the efficiency of provision. Long delays in getting access can allow the disease to get worse, and can lead to avoidable suffering. While it is certain that more skilled neurologists are needed in Ireland, there is also a strong case for looking carefully at the needs to strengthen all parts of the systems of managing neurological diseases. To a large extent there is scope for and interest in strengthening the role of primary care professionals in continuing care, but this will require support from secondary and tertiary services, and will need some strengthening of the capacity in primary care. Equally the roles for general physicians and neurologists (both in secondary and tertiary settings) will need to be clarified and strengthened.

The economic viewpoint will be useful in trying to use most efficiently the skills (and the related costs) in each part of the system. Roles for nurse specialists may evolve and may allow better care at the same or lower costs. Better information systems may allow more systematic and, in some cases, less frequent use of specialists. Gate keeping is often seen as a key tool for controlling costs in secondary and tertiary care, and in many cases this is true. However, where the necessary skills are at higher levels in the system it can simply represent a wasted visit. In some neurological disorders the role of primary care can be in the maintenance of the patient in the community more than in the primary diagnostic and treatment planning processes.

Reviews of the cost-effectiveness of new treatments for some diseases (such as multiple sclerosis) demonstrate the need for more extensive research to build up the quality of evidence. While there is now clearer evidence of the effectiveness of some drug treatments, there remains some uncertainty about the best choices and the most cost-effective strategies. Adding an economic dimension to studies can help to provide more convincing evidence that shows not only what works, but also what works well enough to be a priority in the use of resources.

Despite the rapid rise in the total resources for health services in Ireland in the past decade, the improvements in neurology services have been slow. The likely constraints in new resources in the coming years require strategies both to make service delivery more efficient (thus releasing resources to improve access) and to demonstrate more clearly that better neurology services are likely to be both effective and cost-effective.

### Cost/ benefit of neurorehabilitation: The economic case

The forthcoming (at the time of writing) National Neurorehabilitation Strategy notes that "research on the health economics of neurorehabilitation indicates that there are significant and substantial benefits to be had from these services and, in many instances, they make sound economic sense".

The strategy summarises in detail the economic benefits of neurorehabilitation in relation to a range of neurological conditions, including stroke, acquired brain injury (ABI), multiple sclerosis and spinal injuries.

For stroke, intensive hospital based neurorehabilitation in dedicated stroke units has been shown to improve functional outcomes and reduce the length of hospital stays.

In relation to ABI, a range of studies highlight the potential substantial and significant benefits to be had from rehabilitation, even among the most severely injured. Benefits include reduced need for supervision, improved vocational reintegration and increased ability to perform activities of daily living. Vocational rehabilitation programmes have been found to be economically efficient in allowing people to return to paid employment.

The key messages from this detailed overview of the economic case for neurorehabilitation are:

- the earlier neurorehabilitation commences, the greater the economic benefit in terms of better outcomes and reduced hospital stay;
- particular evidence was found for the effectiveness of community based neurorehabilitation services;
- benefits of specialised multidisciplinary condition-specific teams for the rehabilitation of stroke, ABI, multiple sclerosis and spinal cord injury.

(Note: This section is intended to provide only the briefest overview of this subject and is not intended as a comprehensive treatment of this complex aspect of the management of neurological conditions. A more detailed discussion is available in the forthcoming National Neurorehabilitation Strategy and through examination of the series of literature reviews in this area.)

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## **PART II**

### **THE OPPORTUNITY**

**Chapter 5:** The role of the National Disability Strategy in addressing the needs of people with a neurological condition

Ms Angela Kerins

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“My son Karl is 20 years old; he was diagnosed with Idiopathic Torsion Dystonia at 5 years of age. Karl has been on various forms of medications and attends his neurologist in Dublin. Life is very difficult for Karl. Because of his dystonia his IQ is affected, he can't read, his voice...he cannot speak or communicate. Even if he had a computer he cannot spell and both his arms are affected because he has no fine movements. Services were in place for Karl up to 18 years. At present I am trying to get him into a rehabilitation centre where he can have speech therapy, occupational therapy and make some friends before he suffers depression.”

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## **Chapter 5 - The role of the National Disability Strategy in addressing the needs of people with a neurological condition**

### **Angela Kerins, Chief Executive Officer, Rehab Group**

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#### **Introduction**

Launched in 2004, the National Disability Strategy is the first-ever whole of government response to disability in Ireland, and the result of many years' work, initially of campaigning by disability organisations and committed individuals, and, latterly, of work by these groups in a formal relationship with government departments, public representatives, state agencies and other stakeholders.

The strategy comprises a package of legislative, policy and financial measures designed to advance the public services provided to people with disabilities in Ireland. It includes as an integral part a monitoring mechanism, which sees people with disabilities and disability service organisations meet regularly with government officials to monitor the progress of the plan. It is a method unique in Europe, and possibly in the wider world. Moreover, it is a crucial piece of the disability policy jigsaw in Ireland.

The National Disability Strategy recognised for the first time that people with disabilities needed to be considered in an individual way in terms of all of their needs. Those involved in the strategy's development wanted to establish a policy and legislative infrastructure, which would cater for the needs of people with disabilities regardless of the nature of their disability. They looked at how people live their lives, at how they interact with the State – from birth to old age through their schooling and training, working lives, need for care and support, caring responsibilities, travel, leisure and their access to life in the community – and tried to support those people to make their own lives better.

#### **The National Disability Strategy and people with neurological conditions**

The strategy has many resonances for people with a neurological condition. Given the vast range of neurological conditions and the consequent range of experiences of people with such conditions, there are elements of the strategy that will, if fully implemented, impact on the lives of many. These range from the statutory right to an assessment of health and educational needs, to the provisions requiring greater physical access to the built environment, to public transport improvements. The strategy contains elements that impact across the life cycle and across the range of services that are offered to the public. It fundamentally changes how those services will be offered to people with disabilities.

The major challenge in the current climate is to ensure that the strategy remains to the forefront of Government policy, that its full potential is reached and that a successive strategy is raised to ensure continuous progress.

#### **Origins**

The report of the Commission on the Status of People with Disabilities (1996), recognised the lack of legislation and the systemic failures that existed in relation to all services including health, education, employment, transport and access for people with disabilities. In all, the 402 recommendations emerged from a two-year historic consultation process during which listening meetings took place with people with disabilities all over the country. For the first time, people with disabilities and their families, carers and representatives had the opportunity to play a role in a major national report. This report set the agenda for the next number of years.

Following on from the Commission's report, and using its guiding principles, an 'establishment group' was set up, whose membership included all the key government departments and individuals, with a remit to give an operational format to the broad proposals of the Commission's report.

In 1998 this group published its plan Building a Future Together and oversaw: the establishment needs of the National Disability Authority (NDA); the moving of responsibility for training from the National Rehabilitation Board (NRB) to FÁS; the change in responsibility for providing information about services and entitlements for people with disabilities from the NRB to the Citizens Information Board, and of the audiology services to the Department of Health and Children.

The ensuing decade saw developments such as the Employment Equality Acts 1998 and 2004 and the Equal Status Acts 2000 to 2004. However, while Ireland came to the forefront of equal status legislation, a clear appetite existed for the development of legislation that specifically provided for positive statements in Irish law about the services to which people with disabilities are entitled, across all government departments.



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In 2001, the Disability Bill was published by the Irish Government. Difficulties arose in relation to the content of the bill, and it was withdrawn to make way for a period of consultation with all stakeholders to inform new legislation. Over the next number of years, the government of the day demonstrated its commitment to the full involvement of the disability sector in the development of policy and legislation in this area by establishing a formal consultation process.

This was a significant move, as it was the first time that the government went into structured consultation with the disability sector and also the first time that the eight umbrella bodies, representing over 500 disability organisations and thousands of people with disabilities, had come together. This initiative was called the Disability Legislation Consultation Group (DLCG).

Through the DLCG, the sector worked together with the support of the NDA to identify the 10 core elements which it wished to see included in disability legislation. These included the introduction of an independent assessment of need and service co-ordination, advocacy, mainstreaming, accessibility, disability awareness training and public service employment. These are all detailed in the DLCG document *Equal Citizens* (2003), which set out for government the key elements to be contained in the new Disability Bill. The DLCG engaged in substantial lobbying across all political parties and government departments in support of these elements. It is fair to say that this structure is acknowledged internationally as best practice in stakeholder engagement and output.

The National Disability Strategy (Department of Justice, Equality and Law Reform, 2004) was launched by the Irish Government in 2004, and comprised four pillars: legislation, sectoral plans of six government departments, a multi-million, multi-annual investment programme and crucially, a monitoring mechanism involving all stakeholders.

### **Elements of the National Disability Strategy**

The strategy built on existing policy and legislation, including the policy of mainstreaming public services for people with disabilities.

The key elements of the strategy are:

- the Disability Act 2005;
- the Citizens' Information Act 2007;
- sectoral plans published by six government departments;
- the Education for Persons with Special Educational Needs Act 2004;
- a multi-annual investment programme to run from 2005 until 2009, worth over €900 million and targeted at high-priority disability support services.

A lynchpin of the strategy, the Disability Act 2005 was designed to advance and underpin the participation of people with disabilities in society by supporting the provision of disability-specific services and improving access to mainstream public services. The Act puts in place a strong framework, which seeks to make significant and long-term improvements to the lives of people with disabilities.

The Independent Assessment of Need (IAN) contained in the Act was cautiously welcomed by stakeholders. Still, the need to relate the outcome of the assessment to the provision of services was a cause of some concern and was actively raised over the course of the Bill's passage through the Oireachtas. In 2007, the IAN was commenced for children aged under five years along with the publication of standards for its implementation by the Health Information and Quality Authority. Unfortunately, further roll-out beyond age five has been delayed due to public sector cutbacks.

The Act's positive action elements have been more successful, with the 3 per cent quota for the employment of people with disabilities being achieved in most government departments and related agencies. This quota is monitored annually by the National Disability Authority. The provisions relating to improving the accessibility of all public buildings by 2015 and the publication of a code of practice for access to public services have the potential to create a society where physical and information obstacles no longer prevent a person with a disability participating in their community. A great deal of progress has been made in ensuring that people with disabilities can access local public buildings and transport links, but more work is required if accessible buildings are to become the norm throughout the country.

Progress has also been made in relation to the development of strong, active mechanisms to monitor the strategy. The National Disability Strategy Stakeholders' Monitoring Group meets twice a year to bring together senior officials of the departments and agencies responsible for rolling out the strategy and key representatives of the disability sector under the umbrella of the Disability Stakeholders Group (DSG). A strong reporting structure based on clear objectives and timeframes has been developed.

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Under the Disability Act 2005, six government departments (Health and Children; the formerly named Enterprise, Trade and Employment; Environment, Heritage and Local Government; the formerly named Social and Family Affairs; Communications, Energy and Natural Resources; and Transport) were required to develop three-year sectoral plans outlining their commitments and services for people with disabilities. It is the case that these plans have delivered considerable improvements for people with disabilities, particularly in the areas of accessibility of buildings, services and information. New sectoral plans are due to be placed before the Houses of the Oireachtas shortly, coming at a time when restrictions on funding could impact on the aspirations of Irish society in progressing the position of people with disabilities.

Throughout the National Disability Strategy, the importance of inter-departmental co-operation recognises that the lives of people with disabilities do not fit neatly into the remit of one government department.

The Disability Act requires each of the six sectoral plan departments to lay out how each will interact formally with other departments. This has enabled more ambitious goals, which require cross-departmental support. For example, the Department of Enterprise, Trade and Employment set a target of increasing the number of people with disabilities in employment by 7,000 (Department of Enterprise, Trade and Employment, 2006, p11).

This target requires the support of the Departments of Social Protection and Health and Children, and of the non-statutory disability sector, in order to be successful.

### **Neurological conditions and the Disability Act 2005**

Specific attention was paid in this process to the needs of people with a neurological condition. In particular, the needs of people with episodic conditions were considered in detail both prior to the publication of the Disability Bill and during its passage through the Oireachtas. The DLCG wanted to ensure that the needs of people whose disability changes over time were fully covered by the legislation.

The Disability Act itself defines disability in Section 2 as “disability, in relation to a person, means a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the state or to participate in social or cultural life in the state by reason of an enduring physical, sensory, mental health or intellectual impairment” (Disability Act, 2005).

A key term in this definition, ‘enduring’, was the subject of debate in the Oireachtas in 2005. Public representatives expressed concerns based on submissions by organisations representing those with neurological conditions and mental health issues. They feared the term would be interpreted as excluding those with conditions that are episodic in nature.

This was reported on a number of occasions, and seemed to be finally addressed, at least in the Oireachtas, when Frank Fahey TD, in response to an amendment tabled by a number of senators, stated: “an enduring disability means that the underlying condition is enduring and not one that must have symptoms or signs of the condition at the time. I confirm that is the case, that is, that people so described by Senator (Mary) Henry are included in the definition of the Bill and, consequently, multiple sclerosis is so included (Seanad Éireann, 2005)”.

The deferral of the rollout of the IAN has, without doubt, postponed the positive impact of the strategy for many (Citizens Information Board, 2009). It is of vital importance that this rollout is done to ascertain people’s needs and for proper planning of future services to ensure the optimum and fair use of available resources.

Episodic neurological conditions can vary from mild to severe over time. The requirement to develop a service statement with reference to available resources may cause difficulties for an individual with a neurological condition who is currently only experiencing mild symptoms. It is therefore vitally important that disability stakeholders bring the commitments made in the Oireachtas to the attention of the officials implementing the IAN under the Act.

### **The effect of the economic downturn on the National Disability Strategy**

The onset of the recession impacted quickly on the commitments of the National Disability Strategy which remain to be fulfilled. In early 2008, the HSE indicated that it would not implement the rollout of the IAN for those aged five years and over for the foreseeable future. Other items that have been put on hold include the rollout of the advocacy service and the National Carers’ Strategy.

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In tandem with developments in the fields of equality and disability during the first decade of this century, a great deal of progress has been made in the provision of supports for carers. Increases to carer-related social welfare payments and respite grants, as well as the development and availability of some high-quality respite care services, have gradually recognised the huge contribution made by carers. The programme developed at the formation of the new Fianna Fáil/Green Party Government in 2007 included a commitment to ensuring the development of a National Carers' Strategy (Government of Ireland, 2007) focusing on supporting informal and family carers in the community. This was widely welcomed within the sector.

Unfortunately, following a great deal of engagement with carers' representatives, a decision was taken in early 2009 not to publish the National Carers' Strategy (The Irish Times, 2009) because of a lack of funding for its implementation. This is very unhelpful as while everyone recognises that finance is difficult, finance is not the only issue. As we have seen with the Disability Strategy, progress not only relates to funding but also to attitudes and ways of working. Also, a strategy would provide a basis for measuring impact of existing funding.

Another key pillar of the National Disability Strategy that has also been postponed is the statutory Personal Advocacy Service (Department of Social and Family Affairs, 2009), legislated for by the Citizens Information Act 2007. The development of community advocacy projects by the Citizens Information Board throughout the country in some ways bridges this gap but fails to provide for the needs of people in hard-to-reach places, some of whom could be at risk of harm in terms of their health or welfare.

### **Pressing on with the implementation of the National Disability Strategy**

The disability sector has demonstrated strength in unity over the years. As we continue to press for the full implementation of the National Disability Strategy we do so now in a period of recession.

Now more than ever, disability organisations and representative bodies must work together and drive the full implementation of the strategy. The implementation of the IAN could change the face of disability services in this country. It would ensure that service need is independently identified at local level based on an individual's needs. The aggregate results of the assessments of need would allow the government to plan for future need as set out in the Disability Act.

The publication in October of the Renewed Programme for Government reiterated the government's support for the strategy with the proposed development of a National Disability Strategy Recession Implementation Plan (Government of Ireland, 2009, p19), central to which will be the availability of accessible public and social services to vindicate the rights of people with disabilities to full participation within the State. It will be the role of the disability sector to push for the implementation of the elements of the strategy, which will make the most difference to the lives of people with disabilities. These may be the hardest-fought battles but the implementation of elements such as the IAN, the achievement of the targets under the Comprehensive Employment Strategy for People with Disabilities (unpublished), the personal advocacy services and initiatives for carers are key to achieving the goals set out in the original strategy.

It is also very important that the monitoring mechanisms for the National Disability Strategy remain in place and remain robust. If this is not the case the disability sector will have lost not only its ability to actively review the implementation of the strategy but its powerful base of common purpose.

### **Conclusion**

All of us must continue to strive to ensure that the position of people with disabilities continues to progress, that the National Disability Strategy is delivered in its entirety in the shortest possible timescale. We must put aside old and outdated opinions and politics and work together to ensure that our adults and children with disabilities get their fair and equal opportunity to participate in the economic, political, cultural and social life of this nation.

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## PART II THE OPPORTUNITY

**Chapter 6:** The vision of the Health Information and Quality Authority (HIQA) for improving services for people with neurological conditions

Dr Tracey Cooper

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“Living with Dystonia has transformed me into a different person completely I have lost all my independence and confidence. It has changed the day to day living of both myself, my husband and daughter. I cannot drive; I have to be driven to hairdressers and places like that. I had to give up work due to bad concentration, my memory seems to stray somewhat. My vision and speech are affected, my tongue gets very sore when talking for any length of time. I have lost interest in shopping. I am in bed by 8.30p.m., no social life at weekends no interest in meeting my friends.”

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**Chapter 6:** The vision of the Health Information and Quality Authority (HIQA) for improving services for people with neurological conditions  
**Dr Tracey Cooper, Chief Executive, HIQA**

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## Introduction

HIQA drives safety and quality improvements for users of health and social care services in Ireland. We have been doing this since our establishment in 2007 through the introduction of new standards for providers and the transparent and fair monitoring of how these standards are being implemented.

In 2003, the government launched the Health Service Reform Programme, under which the Authority was established. Our remit extends across the spectrum of services in the public, private and voluntary sectors. Our statutory responsibilities include:

- developing quality and safety standards, based on evidence and international best practice, for health and social care services in Ireland, other than in the area of mental health services;
- registering and inspecting residential homes for children, older people and people with disabilities, as well as inspecting children detention schools and foster care services;
- monitoring standards of quality and safety in our health services, and investigating, as necessary, serious concerns about the health and welfare of service users;
- ensuring the best outcome for people using the services by evaluating the clinical and economic effectiveness of medications, medical devices, diagnostics techniques and health promotion activities;
- advising on the collection and sharing of information across the services, evaluating and publishing information about the delivery and performance of Ireland's health and social care services.

## Making a real impact

In fulfilling its role, HIQA works with the people who are providing services and those who are using services in order to ensure that our work is real and makes sense to the priorities in the system at any given point in time. An example of this approach in recent times has been our focus on breast cancer services. The eventual expansion of the remit of HIQA will be a significant development towards protecting vulnerable groups in our society.

Ireland is unique in the world in establishing an independent health care standards and quality agency with the legislative powers to set, monitor and investigate health care and social care standards, to evaluate the effectiveness of medicines and treatments, and to advise on the gathering and sharing of health information across the health and social care services. While the Authority has been in existence for a relatively short period of time, we believe we are already making an impact on safety and quality for service users. We have carried out extensive investigations into individual episodes of breast cancer care, commenced inspection of hygiene standards in acute hospitals, and introduced a new public-friendly system of nursing home inspections.

In addition, we have conducted health technology assessments covering the introduction of a colorectal cancer screening programme in Ireland and the introduction of a cervical cancer vaccination programme. Both of these programmes have now been accepted as government policy following recommendations made by the Authority and they will be rolled out in the coming years. We have also carefully considered the vitally important use of personal identification numbers in the health and social care settings, and have recommended a Unique Health Identifier for health care and social care users in the interest of safety.

## Protecting the most vulnerable

Our work is aimed at protecting the most vulnerable users of health and social care services. It spans the spectrum of very young service users in the case of children's residential services and services for people with disabilities, to older people in the case of nursing homes and residential care services. We believe that improved practice in one area of health and social care can be of enormous benefit to fostering a culture of safety and learning in other areas, changing the approach of people towards improving their services and making services more accountable to the people who use them.

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## **HIQA and neurological conditions**

The families of people who suffer from neurological conditions might ask what relevance has the work of HIQA to them. The Commission on Patient Safety and Quality Assurance has recommended that the Authority take on a wider regulatory remit. The Minister for Health and Children, Mary Harney TD, has announced vitally important measures to implement the Report of the commission, principally, the government's decision to prepare the legal basis for the licensing of public and private health care providers. This work will be carried out by the Authority. Licensing will encompass objective, mandatory standards, and compliance with these standards will be legally required for every hospital or health care provider. The Authority endorses the commission's recommendation of a health service-wide system of governance based on corporate accountability for the implementation of nationally agreed administrative and clinical standards.

We also fully support its recommendation for a mandatory system of adverse event reporting, legal protection or privilege for open disclosure, which is undertaken in good faith. In future, hospitals providing neurological services will have to meet certain criteria under this new system of licensing in order to be approved by the Authority to provide their range of services. In the current economic climate, there are huge challenges facing providers and those funding our health and social care services. However, there is much that can be, and is being, done to improve services. Changing culture in the health and social care services is not always resource dependent; rather it is based on how we do things differently. We must all strive to encourage a culture of safety and learning in all health and social care settings regardless of the economic challenges we face.

## **Publishing our findings**

Meanwhile, we publish all of the reports of the inspections of residential care centres for older people and children's residential services, allowing service providers in this area and in other fields to compare and learn from each other's best practice. In a similar vein, the publication of our acute hospital hygiene inspections allows providers to study where they can improve their own services. Indeed, the publication of these reports helps to generate a culture of openness and a willingness to improve practice. Staff providing health and social care services must be supported and encouraged where they are providing good care and the Authority has a key role in enabling the sharing of best practice across services, through the publication of such reports.

## **Conclusion: Looking to the future**

In 2010, the Authority will host a major international conference on health technology assessment, an area of interest and direct relevance for patients and families seeking the best possible outcomes for their loved ones receiving treatment in hospital. The Authority wants to support service providers to deliver services that are person centred and that meet the needs of the people who use these services. Setting standards that reflect these principles, in addition to standards on corporate governance and clear accountability, will provide service users with a clear understanding of what they have a right to expect. Standards, when combined with inspection and registration, provide clarity of expectations and external accountability, and the Authority looks forward to working with all those in the sector to help drive improvements for the benefit of all. We will continue to support providers to provide safer and better care and will continue to publicly highlight where improvements are needed to attain this worthy goal.

## PART I THE CHALLENGE

### Chapter 7: Knowledge for health: Neurological conditions and research

Introduction the Neurological Alliance of Ireland  
With Contributions from MRCG and IICN

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“I am 50 years old and I am married with four children. I have suffered with generalised dystonia for the past 16 years and I have suffered a long and arduous journey through doctors, neurologists, and various treatments. I have been very fortunate in that my doctors treating me in Ireland have made sure that I’ve had access to best possible treatments available here but even with that, my dystonia got so bad that it seemed to affect every part of my body. In consultation with my neurologist, it was suggested that I may benefit from deep brain stimulation (DBS) surgery if I was a suitable candidate. And so, I began another journey, which took me to Oxford, England as DBS. was unavailable in Ireland. It has been a very lonely experience as the distance between Dublin and Oxford has meant travelling without the support of my family or friends, but I have been fortunate as the DBS surgery has worked well for me. I’m still required to travel back yearly to Oxford to have my battery checked and even though the facilities exist here, a lack of funding means that the teams needed to staff this treatment can’t be put into action. It just doesn’t make sense as we have the best neurologists and neurosurgeons here in Ireland yet we are forced to send people who need this treatment abroad.”

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## **Chapter 7 - Knowledge for health: Neurological conditions and research.**

Introduction by the Neurological Alliance of Ireland

### **Contributions by the Irish Institute of Clinical Neuroscience (IICN) and the Medical Research Charities Group (MRCG)**

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#### **Introduction**

Health research is a broad term, which covers a diverse range of activities and applications. The full pathway of health research encompasses the entire journey from the generation of new ideas, through their transformation into something useful, to their implementation. It spans the spectrum of activity from biomedical research, life sciences and new emerging technologies, through to clinical and patient-oriented research, and onto population health sciences and health-services research. It can lead to new and more cost-effective services, products, methods, management practices and policies to improve health outcomes which benefit everyone.

#### **Action Plan for Health Research 2009 – 13**

Research is a key component in improving the health and quality of life for people with neurological conditions. Investigations to improve the understanding of particular conditions, translational research into how this knowledge can be useful and practical, what interventions can be beneficial and how service delivery can positively impact, are all considerations driving the research agenda. This is most often stimulated by the scientific and social science community and the desire of people with neurological conditions to better understand, manage, prevent or, in many cases, cure their conditions. Aligned to these driving forces are the many commercial aspects of research and responsibility of the state to provide more efficacious and appropriate responses to population health.

The investment in research, neurological or otherwise, comes from a number of key sources. In 2008, public expenditure on health research, through various government departments and their respective agencies (Health Research Board, Science Foundation Ireland, Irish Development Authority etc.), stood at €200 million. In terms of private sector spending, 2007 figures estimate that €1.6 billion was spent on health research. The MRCG, an umbrella body for charities involved in medical research estimates that between 2006 and 2010 charities will have invested €56.6 million in health research. In all of these calculations, however, there is no figure for neurological specific research.

There are many challenges and opportunities in the neurological research arena. The underinvestment in neurology in general, as identified in the unpublished Laffoy report, Strategic Review of Neurology and Clinical Neurophysiology Services, certainly has an impact on the resources available in the hospital setting. The time, space, equipment and facilities available to neurological teams are most often prioritised based on direct patient services (diagnosis, treatment, clinics etc.). This prioritisation of service delivery over research is often replicated too in the charitable sector. Research grants awarded by charities are often costly, and with limited resources, charities opt for services that have a direct impact on services users. However, without research the treatments, interventions and services delivered cease to be innovative, and ultimately do not develop to the benefit of the patient.

Another significant challenge in the area of research is the number of agencies and institutions involved in funding or conducting research and their ability to communicate and collaborate appropriately. There are a number of funding bodies for example – public, private and charitable – that award funding based on their particular agenda or area of expertise. However, many of these agendas overlap and while one agency may specialise in health research and another in scientific research, many neurological research projects span both these areas. While it is desirable for the researcher to avail of multiple funding opportunities, the presence of many agencies can lead to difficulties relating to duplication of research, shifting standards and competition among researchers and institutions. This reduces effective collaboration and sharing of resources.

There are many opportunities in health research that will come to have a significant impact on neurological research. In the Celtic Tiger era building a smart economy included the stimulation and attraction of much biomedical research under the tenet of research, development and innovation. This type of research, concerned with the biological process of disease, has formed many of the building blocks to bring research from 'bench to bed'. Commonly known as translational research, it is concerned with the transformation of scientific research into practical solutions for the patient.

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Another opportunity is the importance now placed on health research by the government. In early 2010, the Department of Health and Children launched its Action Plan for Health, detailing the many ways in which a world-class health research system can be created by the State, its agencies and other key stakeholders. The plan is an overarching document, which aims to tackle strategy, policy, standards, education and training, funding and infrastructure. While it offers no specific direction to neurological research (or any other branch of research), it does signal a commitment from the government and a clear pathway to improve the Irish research agenda.

Research is the cornerstone of developing appropriate, innovative, patient-centred and effective responses to the needs of people with neurological conditions. Whether scientific or social in nature, it has a key role to play in improving the research landscape in Ireland.

The two sections below examine two key stakeholders in the area of neurological research. The MRCG explores the investment charitable organisations have made to research into their respective conditions and diseases while the IICN focuses on the contribution made to clinical neuroscience by various medical, academic and research institutions and individuals.

### **Research in the charity sector**

#### **Ms Denise Cremins, Development Executive and Mr John McCormack, Chairman, MRCG**

MRCG is an umbrella group of medical research and patient support charities, which originally formed to represent the joint interests of charities specialising in restoring health through medical research, diagnosis and treatment and, where possible, the prevention of disease. A core belief of the group is that today's health research is tomorrow's health care. The founding members of the MRCG came together in 1998 to discuss and determine how the medical research charities in Ireland could work together more effectively. The founding members were Fighting Blindness, the Irish Cancer Society, the Irish Heart Foundation, Alpha One Foundation, Children's Medical and Research Foundation, Crumlin, and DEBRA Ireland.

### **Charity funded research in Ireland**

In 2008, the MRCG undertook a survey of its members to establish their research spending over a six year period, 2005 to 2010. Of the 23 member organisations that responded, a total of €60 million was allocated for investment in medical research. Based on an informal survey of MRCG members in June 2009, it was estimated that MRCG members indirectly employ in the region of 100 researchers.

Research by the Health Research Board (HRB) indicates that health-related expenditure by state-funded agencies in Ireland in 2008 was €198.9 million (Action Plan for Health Research, 2009). In comparison to this, the MRCG investment in medical research equates to 5 per cent of all statutory agencies' health-related research expenditure. The percentage would be much larger if research focused capital investment were removed from the equation.

The charity research spend equates to 28.5 per cent of the total research spend (excluding operational expenses) of the HRB. This is a startlingly high figure, and illustrates the huge contribution that research projects privately funded through patient organisations or charities are making towards the development of the clinical research environment and the knowledge economy in Ireland.

MRCG members set high standards for their patient driven research. Funded projects are rigorously peer reviewed and collaboration with internationally recognised centres of excellence is the norm. This ensures that focused, cutting edge research is undertaken. Patient beneficial outcomes are expected from research funded by MRCG members.

Patient-focused research, funded and supported by charities in Ireland, has had a massive international impact. Researchers funded by Fighting Blindness (a founding member of MRCG) were the first in the world to discover the gene responsible for the blinding condition Retinitis Pigmentosa (McWilliam et al., 1989). Some of the founding research of the Smurfit Genetics Centre was also funded by Fighting Blindness.

Other research organisations have worked to develop research programmes in Ireland in particular disease areas, where no such work was being undertaken in Ireland previously. This research includes that funded by the Cystinosis Foundation of Ireland, which now funds projects in both University College Dublin and University College Cork. Prior to this charity's investment, no research into the rare condition, Cystinosis, was taking place in Ireland. Another example of innovative charity-funded research was the development of the STING procedure in the Children's Research Centre, Our Lady's Children Hospital, Crumlin, research which was funded by the Children's Medical and Research Foundation (Puri et al., 2005). This innovative procedure reduces the need for a potentially lengthy hospital stay and is increasingly used internationally in the treatment of vesicoureteral reflux (VUR), the reverse flow of urine from the bladder into the ureter and kidney.

Irish research charities also work to build capacity among Irish researchers. This includes both bringing novel research areas to Ireland and funding scholarships and fellowships to develop research talent here.

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## **The MRCG**

The vision of the MRCG is to provide a sustaining and integrating influence across the medical research community, promoting scientific, clinical and paramedical research. The MRCG believes that patient organisations should lead and stimulate critical medical research needed by patients, and will provide leadership and support to charities in Ireland that are engaged in medical research.

MRCG's mission is to generate a dynamic medical research environment in Ireland, which will be achieved by partnership with external organisations; advocacy to enable change; a forum to promote education and integration, and the provision of direct services to members.

The MRCG has identified four goals for achieving its mission: increase the funding for medical research in Ireland; remove the barriers to medical research in Ireland; increase the profile of medical research in Ireland, and provide the services and supports members require.

An original aim of the MRCG was to secure statutory funding for medical research, and since 2006 this has operated through a joint funding scheme with the HRB. Under this scheme, 50 per cent of the cost of a successful research programme is funded by the HRB, with the balance of the funds being paid by the sponsoring charity. This innovative scheme allows members of the MRCG to support research of particular interest to a patient population, where they might otherwise not be in a position to finance the full cost of that research. In three funding rounds, 56 projects, for which funding otherwise might not have been available, have been supported. These have included research into very rare conditions with very small patient populations in Ireland, as well as research into more commonly occurring diseases.

Like all patient-focused charities, the main goal of MRCG is to alleviate suffering and mortality from illness in Ireland and internationally. It is dedicated to improving health and well-being by promoting medical research, by generating resources for this end and by encouraging and supporting medical research in Ireland. MRCG has also been recognised as a contributor to health research in the recently published Action Plan for Health Research, 2009 – 13 (2009).

## **Clinical neuroscience research in Ireland, and the role of the Irish Institute of Clinical Neuroscience (IICN)**

Dr Catherine Keohane, Vice-Dean, IICN

### **Introduction**

Clinical neurosciences are those specialties that involve the investigation, management, diagnosis and treatment of adults and children with diseases affecting the nervous system, including disorders of the brain, spinal cord nerves and muscles. Research in clinical neurosciences encompasses many aspects of these conditions including data on the causative factors (epidemiology), genetic influences, new diagnostic tests and methods of investigation, as well as pathological mechanisms of how the disorder affects the nervous and neuromuscular tissues, and the influence of various treatments.

There is also an overlap with those involved in caring for patients with disorders of the special senses (eye and ear) and neuropsychological diseases. Research in clinical neuroscience in Ireland, both North and south, is conducted by almost all clinicians, often in conjunction with university departments. A multidisciplinary approach, looking at many different aspects of a disorder is often the most productive in terms of meaningful results. In practice, for rarer disorders many departments have links and collaborate with other international centres so that statistically significant results can be gained from pooled data.

Although it is a requirement of the consultant contract to conduct research, the reality is that due to the sheer pressures of the numbers of patients to be seen at clinics, investigated and treated, most research activities have to be conducted 'out of hours', late in the evenings or at weekends, or both! Very few departments can devote protected time to research. Nonetheless, it is an important part of most departments' practice.

Some university medical schools do not have an academic chair in clinical neurosciences. This results in an uphill battle for those competing for research funding with other established professorial departments that have protected academic time. It also perhaps sends out the wrong signals to research bodies, as it suggests that clinical neurosciences are not 'worthy' of an academic chair.

## Promoting research

One of the goals of the IICN is to promote research in clinical neurosciences in Ireland. The Institute was established in 1984, with the objectives of “teaching and education of persons in the knowledge of, promotion and organisation of research into the diagnosis and treatment of neurological and neurosurgical disorders in Ireland”. These remain the core objectives, and are supported by members in centres throughout Ireland and abroad. Almost all clinical neurosciences consultants in Ireland, North and south, are active members of the IICN.

Through the generosity of donors, and commercial sponsors, many worthwhile projects have been funded in a wide variety of subjects including multiple sclerosis, stroke, movement disorders and neurodegenerative diseases. The role of the public and members of the Neurological Alliance of Ireland (NAI) is gratefully acknowledged in fundraising for research. Even in difficult economic times, it is extraordinary how generous individuals are in devoting time and energy to fundraise, often motivated by their direct experience of a family member or friend affected by a nervous system disease.

Young doctors in training have had their interest stimulated in various research topics, which often results in their specialising in that particular area. Competition for the grants is keen, and appropriate assessors are chosen by the IICN. For grants over €25,000, an external assessor must be included.

### Examples of projects funded by the IICN in 2009

#### Disease area: Multiple sclerosis

Project Title: Studies on the genetic epidemiology of multiple sclerosis in an Irish population

Investigators: Dr Orla Gray and Dr Stanley Hawkins, Belfast.

Project Title: The identification of the molecular pathways and genetic determinants of multiple sclerosis (MS); the role of T lymphocytes

Investigators: Dr Tania Jawad and Dr Tim Lynch, Dublin.

#### Disease area: Stroke

Project Title: Assessment of platelet activation and function in response to different anti-platelet regimens in the early and late phases after ischaemia or TIA

Investigators: Dr Justin Kinsella, Dr Oliver Tobin and Dr Dominick McCabe, Dublin.

#### Disease area: Motor neurone disease (ALS)

Project Title: A population based study of the incidence, prevalence and clinical features of cognitive decline in ALS

Investigators: Dr Julie Pukhan and Prof Orla Hardiman, Dublin.

The IICN/UCB pharma neuroscience bursary award 2009.

#### Disease area: Epilepsy

Project Title: Synaptic input to Neuropeptide Y (NPY) containing neurons in the amygdala of pharmac resistant temporal lobe epilepsy patients

Investigators: Dr Uchenna Okafo, University College Cork.

Project Title: A Pharmaco-Genomic exploration of genetic risk factors in Valproate-induced weight gain in patients with epilepsy

Investigators: Dr Sandya Tirupathi and Dr Gianpiero Cavalerri in the Royal College of Surgeons, Dublin.

## An in-depth look

As a more in-depth example of the type of project funded, the following is an outline summary of the work supervised by Dr Dominick McCabe on the Vascular Neurology Research Programme at Adelaide and Meath National Children’s Hospital (AMNCH) and Trinity College Dublin (TCD).

Dr McCabe is Consultant Neurologist and Clinical Senior Lecturer in Neurology, Honorary Senior Lecturer in Clinical Neurosciences, and Co-Director of the Rapid Access Stroke Prevention Service, AMNCH. He leads an active collaborative research programme at the Vascular Neurology Research Group, Department of Neurology, AMNCH and TCD, run in close collaboration with colleagues from AMNCH, St James's Hospital, Institute of Technology, Tallaght, TCD, RCSI and colleagues in the UK, Canada and the USA. It focuses on translational platelet science, haemostasis in transient ischaemic attacks (TIA), ischaemic stroke and carotid stenosis.

At the core of the programme, Dr McCabe supervises two full-time neurology specialist research registrars or clinical neurosciences PhD students at AMNCH, one of whom is Dr Justin Kinsella who co-ordinates the Platelets and Carotid Stenosis (PACS) study in patients with narrowed carotid arteries in the neck, which either have or have not caused symptoms of TIA or stroke. The study combines clinical information with information from detailed neuro-imaging of narrowed carotid arteries and brain arteries, as well as laboratory tests on blood platelets, the endothelium and the coagulation system, to improve our understanding of the cause of TIA or stroke in patients with carotid stenosis.

The ultimate aim of this research is to determine whether one can predict who should have urgent medical, surgical or interventional treatment for carotid stenosis, thus enhancing primary and secondary stroke prevention in these patients.

Dr Oliver Tobin co-ordinates the TRinity AntiPlatelet Responsiveness (TRAP) study, which investigates the important phenomenon of 'responsiveness' and 'resistance' to commonly prescribed antiplatelet drugs following TIA and stroke. The aim is to establish whether one can translate the novel interesting findings into clinical practice, with a view to tailoring antiplatelet therapy to suit individual patients with ischaemic cerebrovascular disease, and maximise secondary prevention in individuals following TIA or stroke. They are also investigating the mechanisms contributing to responsiveness to antiplatelet therapy as part of an extensive collaborative research programme.

Because stroke is the commonest cause of acquired disability, and the second to third commonest cause of death in adults in the developed world, improvements in understanding the mechanisms causing TIA or stroke, and advances in stroke prevention, will facilitate a reduction in disability and death from cerebrovascular disease.

## Funding research

To facilitate training and education, the IICN awards travel grants to enable clinical neuroscientists in Ireland to travel to centres of excellence abroad, either to learn new skills or to facilitate funding towards a larger project. These have included the Sanofi-Aventis Travel grant to Dr Áine Merwick to undergo training in stroke assessment in Vienna and Dr John McHugh to learn newly developed electrophysiological techniques in London. The IICN this year introduced its own travel grant, which was jointly awarded to Dr Lisa Costello to travel to the Pitie/Salpetriere Hospital in Paris to undertake a clinical fellowship in multiple sclerosis, and Dr Michael Jansen to learn new molecular investigation of brain tumours at the Massachusetts General Hospital, Boston.

The IICN has also administered funds kindly contributed by the Aideen Clark Fund, which has sponsored some of the expenses required to run the Dublin Brain Bank. The Dublin Brain Bank was officially launched at the RCSI's Smurfit Building in Beaumont Hospital, Dublin, in October 2008. The objective of the Brain Bank is to facilitate brain donation through an ethically approved programme of informed consent and to provide Irish clinical and basic neuroscience researchers with access to brain tissue to conduct research into neurological disorders. By encouraging brain donation, the Dublin Brain Bank offers individuals an opportunity to support medical science in a very tangible manner.

Donation of precious brain tissue facilitates research studies that will provide valuable information on the diagnosis and treatment of many common neurological diseases such as Alzheimer's and Parkinson's disease, which ultimately will lead to increased quality of life for patients. Becoming a donor requires that consent be given by individual donors, and that consent is given in the full knowledge of the immediate next-of-kin. During life, an "intention to donate" form is completed and immediately after death the final consent is given by the immediate next of kin who has already been witness to the intention to donate.

The brain tissue is processed in two ways to allow maximum information to be obtained and to ensure the tissue is of use for many years to come. One hemisphere is frozen and stored for use in research. The remaining tissue is fixed in formalin to allow for neuropathologic diagnosis. The Brain Bank storage unit is currently located in the Neuropathology Department at Beaumont Hospital.

By the end of 2009, there were over 80 registered donors with various central nervous system diseases including Parkinson's disease, multiple sclerosis, motor neurone disease, epilepsy and multiple systems atrophy. The development of the Brain Bank will pave the way for a more concentrated and organised approach to human tissue banking, which will facilitate neuroscience research.

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## Facilitating collaborations

In addition to administering grants and bursaries, the IICN also runs a number of scientific meetings at which results of research are presented and discussed. As is so often the case, discussion afterwards leads to collaborative projects on topics of shared interest. These meetings include the Irish Neurological Association meeting, the Irish Neuromuscular Association meeting, the Registrar's Prize in Clinical Neurosciences, the Neurology Update, and a Neurosurgical Update (newly established this year).

At the Irish Neurological Association this year, Dr Jennifer Spillane, working with Dr Aisling Ryan and the Neuromuscular Multidisciplinary Group in Cork, outlined an inclusion body myositis (IBM) study, which has collected clinical pathological data on patients with muscle biopsy-proven IBM. The researchers used the platform of the neuromuscular multidisciplinary meeting established at Cork University Hospital, in conjunction with convener Dr Niamh Bermingham and neurophysiologist Dr Brian McNamara. IBM is an inflammatory and wasting muscle disease usually in patients aged over 50 years, which is very resistant to treatment. There is no specific data regarding the incidence of IBM in Ireland.

This is a very brief and selective reference to a few of the research activities being conducted in Ireland, and which the IICN assists in one way or another. It does not attempt to be a complete picture of our work. Neither does it reflect the enormous contribution of many researchers in a whole variety of clinical neuroscience research not mentioned here. In these times of economic hardship, funding for research is very difficult to obtain. However the long-term gains are such that we must continue to try to produce high quality research answering specific questions posed by the problems that patients with neurological disorders face.

## Acknowledgments

I would like to thank and acknowledge Dr Dominick McCabe for the section on his neurovascular research, Dr Michael Farrell and Ms Niamh Kernan, Co-ordinator, for the section on the Brain Bank, and Dr Aisling Ryan for the section on IBM. I also wish to thank Ms Colette Fitzpatrick, administrator, IICN, for her constant help. I wish the NAI continued success in their endeavours, and particular success with this publication.

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## **PART II** **THE OPPORTUNITY**

**Chapter 8** - The role of key health professionals in the management of neurological conditions

Introduction by the Neurological Alliance of Ireland with individual contributors

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“My brain injury and the physical consequences of it are always there and I can’t ever get away from it. It has affected my relationships a lot – I don’t have that many friends anymore.”

“For me, living after a brain haemorrhage is like living in a body that you are crying to get out of, because you know it’s not really you.”

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## **Chapter 8 - The role of key health professionals in the management of neurological conditions**

### **Introduction by The Neurological Alliance of Ireland with individual contributors**

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#### **Introduction**

This chapter aims to reflect the vital contribution of a range of health professionals to the care and treatment of people with neurological conditions in Ireland. The challenges of working in the field of neurological care in this country are identified through their experiences in meeting the needs of these individuals and their families on a daily basis. Each section has been authored by a representative from their specific field, while emphasising their need to work closely with their colleagues in other areas. The concluding section will outline the importance of a multidisciplinary approach to the management of neurological conditions. There is a critical need to prioritise the development of neurological services in this country to allow this standard of care to be available to all individuals with a neurological condition.

It is understood there are many different people involved in the provision of services and supports to people with neurological conditions in Ireland. This chapter is intended to outline the complexities and challenges of this area by drawing on the work of specific groups, while recognising the contribution of all those involved in working with these individuals and their families to promote their wellbeing and quality of life.

#### **The role of the neuropsychiatrist**

Prof David Cotter MRCPsych PhD, Consultant Psychiatrist, Beaumont Hospital and Department of Psychiatry, Royal College of Surgeons in Ireland

Neuropsychiatry is the branch of medicine dealing with mental disorders attributable to diseases of the nervous system. It preceded the current disciplines of psychiatry and neurology, in as much as psychiatrists and neurologists had a common training (Yudofsky and Hales, 2002). However, neurology and psychiatry subsequently split apart and are typically practised separately. Nevertheless, neuropsychiatry has become a growing subspecialty of psychiatry. It is also closely related to the field of behavioural neurology, which is a subspecialty of neurology that addresses clinical problems of cognition and/or behaviour caused by brain injury or brain disease. In brief, neuropsychiatry is that branch of medicine that deals with the study of mental disorders attributable to diseases of the nervous system.

#### **Role in identifying need**

Psychiatric illness is very common among patients suffering from neurological disorders, but is often missed and left untreated. Thus, one of the main aims of psychiatrists working in this field must be to ensure that there is an increased awareness and understanding of psychiatric problems among this group of patients. This will lead to significant improvements in quality of life among patients with neurological illness.

In general, depression is the most common psychiatric disorder. It can affect up to 50 per cent of people with epilepsy, with similar percentages of patients with Parkinson's disease and multiple sclerosis affected during their lifetime. It is also very common among patients who have acquired brain injury (ABI), typically affecting 20-40 per cent of these patients. Other important psychiatric illnesses that can occur among people with neurological illness include anxiety disorders, dysthymia, personality disorders and psychotic disorders. Psychotic experiences are quite common occurrences in association with epilepsy and they occur typically either immediately before or after a seizure, but can also occur between seizures. Psychotic experiences also occur with Parkinson's disease. In general, these experiences are often self-limiting and seizure and/or medication related, and a psychiatrist is not needed unless the symptoms become persistent or distressing. In terms of its common prevalence, treatability and effects on quality of life, a focus on depression is warranted.

#### **Epilepsy as an example**

Among patients with epilepsy whose epilepsy is difficult to control there are relatively higher prevalence rates of depression (Barry et al., 2008). Wiegartz et al. (1999) found that 40 per cent of patients with lifetime histories of major depressive disorder had never been referred for treatment. Gilliam et al. found that 80 per cent of neurologists do not routinely screen patients with epilepsy for depression. There are many possible reasons for this: heavy clinical workload, lack of time, or perceived lack of expertise in diagnosis and management of mental

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illness (Kanner, 2005). Additionally, clinicians and patients alike may view depressed mood as being 'a normal reaction' to facing a life with seizures and the associated socio-occupational complications. Regardless of the fundamental reasons, the result is that the presence of depressive episodes are often neither reported nor enquired into. Depression in epilepsy can also be atypical in presentation (Barry et al., 2008) and this can complicate its identification.

In recent years, there has been an increasing recognition of the importance of quality of life in epilepsy. Quality of life among people with epilepsy is impaired compared with individuals of the same age and sex in the population (Baker et al., 1997). Quality of life is influenced by epilepsy-related factors such as age at epilepsy onset, demographic factors such as education level, seizure frequency, seizure type and seizure control and medication, but is also heavily influenced by co-morbid depression. Canuet (2009) found that the best predictors of quality of life in epilepsy were depression scores and seizure frequency but that depression provided more than three times the impact of seizure frequency (Canuet et al., 2009). Boylan (2004) found that depression was the most powerful predictor of quality of life in people with treatment-resistant epilepsy. Similar findings have been reported in many other studies (Loring et al., 2004; Pulsipher et al., 2006; Tracy et al., 2007).

Similar findings exist concerning the prevalence of depression following ABI and in Parkinson's disease and multiple sclerosis. The challenge is to identify and to treat these patients as early as possible. How is this done?

### **Increasing awareness**

Patients, neurologists and general practitioners must be more aware of the presence of co-morbid psychiatric illness, its enormous influence on quality of life, and be willing to enquire at interview into the presence of psychiatric symptoms. General utility screening tools for anxiety and depression such as the Beck's depression inventory (Beck et al., 1996), or disease-specific tools such as the Neurological Disorders Depression Inventory for Epilepsy (Gilliam et al., 2006) are available. They require only a few minutes of questioning and are highly sensitive and very efficient to use, and are an excellent guide to the presence of co-morbid psychiatric disorder.

### **Role in ongoing management; acting as part of the multidisciplinary team (MDT)**

Once identified, patients with co-morbid psychiatric disorder need to be treated. GPs and neurologists can treat depression, and often do. If the patient is thought to suffer from depression and to be in need of referral to a psychiatrist, it is often worthwhile starting him or her on an antidepressant medication at the time of referral to a psychiatrist so that the patient can improve while waiting for the first assessment with a psychiatrist. Local arrangements and understandings can help to ensure that there is a good understanding between the referrer and psychiatrist regarding what are the likely best treatments (Barry et al., 2008) It is also critical that a referral note to a psychiatrist reflects the level of risk and the immediacy problems. Perhaps the patient needs to be seen as a matter of urgency – this must be clear from the referral. While GPs can successfully manage many psychiatric illnesses, the involvement of a psychiatrist or a specialist psychiatrist with experience in neurological disorders, is often needed. This is particularly the case where there is treatment resistant depression or suicidal ideation, bipolar disorder or persistent and disabling psychotic symptoms.

Psychiatrists work with social workers, nurses, psychologists, occupational health experts, physiotherapists and other clinicians as a part of a MDT approach to patient care. Community psychiatrists have access to resources, like day hospitals, and team members such as community psychiatric nurses, which are hugely beneficial to patients and help to generalise improvements from the clinic to the home environment. Access to community nursing is also critical to following up house-bound patients or patients viewed as at-risk. Hospital MDTs, which focus on the care of patients with neurological disorders, incorporate great expertise. The challenge is to extend the influence of the MDT out of the hospital through hospital-based community initiatives.

### **Priority challenges and opportunities**

**1. Brain injury rehabilitation units:** Ireland is deficient in rehabilitation services for this patient group. There is a need for units where rehabilitation can occur in a stepped manner, allowing increasing independence, and be linked to community-supported lodging. There is also a great need for psychiatric care and input into such proposed units.

**2. Neuropsychiatry outreach to community:** Community psychiatry teams are overburdened and poorly resourced, generally, and feel ill-equipped to deal with psychiatric problems that occur in the setting of epilepsy. There is a need for trained community psychiatric nurses working specifically with neuropsychiatry and neurology services to provide an outreach to these patients.

**3. Psychotherapy:** There is a great need in this area. Therapists, be they psychologists, nurses, or social workers, should be trained to work with neuropsychiatric patients to provide specialist counselling and psychotherapy. One suggestion is that the proposed community psychiatry nurses providing outreach would be dual trained to provide psychotherapy.

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4. *Awareness of the need to screen specifically for depression* among patients with neurological illnesses: Stigma remains a problem and likely contributes to patients' slowness to discuss their psychiatric or psychological difficulties. This problem relates to adults, adolescents and children.

### **The role of the geriatrician**

Dr Shaun O'Keeffe, Consultant Geriatrician, Galway University Hospitals and Chairman, the Irish Society of Physicians in Geriatric Medicine

The collective ageing of our populations is one of the most significant triumphs of the 20th century. The primary policy on ageing in Europe, *Towards a Europe of All Ages* (1999), emphasises three main themes for health and older people - prevention, equity of access and an adequate supply of quality care for older people. The specialty of geriatric medicine has developed in response to these specialised needs and has shown itself capable of providing responses to these challenges, which are not only effective in terms of quality of life but also cost-effective and judicious in their use of personnel and resources.

Among the key elements of this approach are:

- a philosophy of assessment and care which is multidisciplinary and holistic;
- a recognition of subtle and atypical presentations of illness in later life;
- capabilities in recognising and dealing with multiple illnesses;
- careful attention to syndromes such as falls, faints, dementia and incontinence, which standard medical care often ignores or compounds;
- training across a spectrum of care, including care in the community, acute geriatric medicine, rehabilitation and palliative care.

Geriatrics is now the largest hospital-based medical specialty, with about 60 consultants, in Ireland.

### **Geriatricians and neurological conditions**

The skills of geriatric medicine are particularly relevant to neurological conditions, which are among the most common and distressing conditions affecting older people and are particularly important because of their impact on disability. The prevalence of stroke disease, dementia and Parkinson's disease in particular all increase substantially with age.

Stroke is the third leading cause of death in Ireland and the leading cause of serious adult physical disability. While stroke can affect people of any age - the average age of onset is 74 - two thirds of people suffering stroke are over 65 years old, one third of nursing home beds in Ireland are occupied by patients with stroke disease and an estimated 30,000, mainly older, people are living with disability post stroke in Ireland.

Dementia is predominantly a disorder of later life. Five per cent of community-dwelling older Irish people suffer from this condition in addition to approximately 50 per cent of hospitalised or institutionalised patients, leading to a total number in excess of 30,000. People with this condition have a reduced life expectancy with greater use of medical services and increased requirement for institutionalised care. It has been estimated that the costs of Alzheimer's disease in Ireland are in excess of €400 million per annum.

Parkinson's disease is common among elderly people. The average age of onset is 60 years and it occurs in about 2 per cent of people aged 75 years or more. In 2003, the World Health Organisation (WHO) noted that the main contributions to disability in later life came from dementia (11 per cent) and stroke (9 per cent). In contrast, all the different forms of cancer contributed only 2 per cent of disability.

### **Geriatricians in Ireland**

Geriatricians have been to the fore in the development of specialist services for stroke and for those with dementia in Ireland. The first organised stroke services were established in the late 1980s by geriatricians, and, outside major teaching hospitals, the majority of what exists in terms of organised stroke services in Irish hospitals has been developed and run by geriatricians with a specialist interest in stroke. Rehabilitation of stroke patients is also predominantly provided by geriatricians. Currently, geriatricians, with their colleagues in neurology, are involved in providing acute stroke services including thrombolysis in many parts of the country. Assessment and management of older people with dementia is shared with colleagues in old age psychiatry. The first Irish Memory Clinic opened in St James's Hospital in 1989 in the first instance with geriatricians and subsequently old age psychiatrists. Academic geriatricians and psychiatrists of old age in Trinity College Dublin have also helped to develop the National Dementia Services Information and Development Centre. Although younger patients with Parkinson's disease usually come under the care of neurologists, many older patients, especially those who develop Parkinson's disease in later life, are cared for by geriatricians. Care by the geriatrician is often appropriate because of the specific co-morbid problems experienced by older Parkinson's disease patients such as recurrent falls, urinary and faecal incontinence and a high frequency of dementia. Stroke and dementia assessment care and management feature prominently in the training programmes of Irish specialist registrars in geriatric medicine.

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## Working as part of a team

A multidisciplinary approach to working is at the heart of the gerontological model of medical care. This co-operative, patient-centred approach is the most effective, holistic way to deliver care to complex patients such as those with neurological conditions. Geriatricians value their close working relationships and collaboration with nursing and allied health professionals and with other specialties including neurology and rehabilitation medicine.

There have been enormous strides in the last decade in our knowledge and understanding of and in our ability to manage neurological diseases of later life. It should also be acknowledged that there have been substantial improvements in service provision and organisation in Ireland. Many of these improvements have resulted from the commitment and hard work of health care professionals. Increased investment in services and expansions in the numbers of nurses and allied health professionals with specific neurological expertise and in the number of geriatricians have been welcome.

## The challenges

A number of significant challenges remain especially in the current era of economic difficulties. Neurological diseases of later life often lack profile or visibility, sometimes as a direct consequence of the illness, sometimes due to an inappropriately nihilistic view of the new treatment possibilities available and sometimes due to ageism.

With the common, increasingly treatable brain diseases of later life, it is frustrating to reflect on the missed opportunities, unnecessary high death and disability rates, and increased costs that arise from a failure to develop co-ordinated stroke and dementia services among others. There remain deficits in the provision of a wide range of professionals needed to treat such disease. In particular, we note the need for additional appointments in neurology and rehabilitation medicine and of allied health professionals. The jobs embargo and freezing of posts in recent times has particularly affected front line staff who work with those with neurological illnesses in the community, hospitals and nursing homes.

## The role of the consultant in rehabilitation medicine

Dr Mark Delargy, Consultant in Rehabilitation Medicine,  
National Rehabilitation Hospital Beaumont and Mater Hospitals

The WHO's definition of rehabilitation is: "The use of all means in reducing the impact of disabling and handicapping conditions and at enabling people with disabilities to achieve optimal social integration." "The European Union of Medical Specialties' (UEMS) section of Physical and Rehabilitation Medicine further defines rehabilitation medicine as "an independent medical specialty concerned with the promotion of physical and cognitive functioning, activities (including behaviour), participation (including quality of life), and modifying personal and environmental factors". It is thus responsible for the prevention, diagnosis, treatment and rehabilitation management of people with disabling medical conditions and morbidity across all ages. In Ireland, physical and rehabilitation medicine (PRM) is known as rehabilitation medicine.

Rehabilitation medicine is guided by the bio-psycho-social approach. It identifies underlying pathology, problems at the level of organ functioning and the potential for restoring/optimising personal function or prevention of further limitation of activity. In addition, it considers the ability to participate in society, which depends not only on personal functioning, but also contextual factors affecting the individual's life and environment.

Rehabilitation can be provided in a number of settings, which range from specialised rehabilitation centres and departments in acute hospitals to outpatient and community settings. Acute rehabilitation is important in order to utilise plasticity as effectively and as early as possible, and to reduce the potential for complications. Acute rehabilitation requires a peripatetic team of rehabilitation professionals able to give advice to all wards in the hospital, including intensive care. Patients with a disability may also require rehabilitation in dedicated rehabilitation facilities directed by rehabilitation medicine specialists. Those with long-standing, often progressive disabilities need access to rehabilitation in the community to ensure that their fitness, health, and abilities are maintained and that their independence is promoted.

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**The competencies of rehabilitation medicine specialists include, amongst others:**

- medical assessment to determine the underlying diagnosis;
- assessment of functional capacity and the ability to adapt and change;
- assessment of activity and participation in the social and health contexts;
- capacity to devise a rehabilitation plan;
- knowledge and experience to apply medical and physical treatments;
- capacity to evaluate and measure outcome from rehabilitation intervention;
- the prevention and management of complications experienced by those with disability;
- providing prognosis on rehabilitation outcomes;
- knowledge of rehabilitation technology;
- team dynamics and leadership skills;
- teaching skills;
- knowledge of social system and legislation on disablement.

As stated earlier in this publication by my colleague Dr Áine Carroll, access to rehabilitation is considered a basic human right. Rehabilitation should be provided by appropriately trained specialists, working in partnership with the person with the disability. The UEMS White Book (2006) on Physical and Rehabilitation Medicine documents that Ireland has the lowest number of rehabilitation medicine specialists per 100,000 population. The United Kingdom has double the number of rehabilitation medicine doctors per 100,000 population. The Netherlands have 13 times the number of rehabilitation medicine specialists as Ireland per 100,000 population. Norway, with a similar population to Ireland, had 183 practising rehabilitation medicine specialists in 2006 whereas Ireland had only five specialists in rehabilitation medicine. It is therefore inevitable that access to rehabilitation medicine is very much more difficult in Ireland than in any other country in Western Europe and this situation needs to improve dramatically.

**The following is a list of examples of disabling neurological conditions commonly encountered by rehabilitation medicine specialists in Ireland:**

- stroke, including sub-arachnoid haemorrhage and vasculitides;
- traumatic brain injury;
- spinal cord injury and compression syndromes;
- multiple and complex neurological trauma, including brachial plexus and peripheral nerve injuries;
- central nervous system infections and abscesses;
- central nervous system benign and low-grade tumours;
- peripheral neuropathies, including Guillain-Barré disease;
- congenital conditions such as cerebral palsy and spina bifida;
- neurogenic pain conditions arising from amputation, stroke, spinal cord injury and traumatic brain injury;
- neurological problems, including incontinence;
- neurological erectile dysfunction.

**The rehabilitation medicine specialist works as a member of an inter-disciplinary rehabilitation team. The rehabilitation medicine specialist has specific training in addressing general problems that emerge across many health conditions. These problems may include:**

- prolonged bed-rest and immobilisation;
- deconditioning from immobility resulting in loss of physical and psychological function;
- motor deficits producing weakness and loss of personal functioning;
- spasticity leading to limb deformity and self-image problems;
- bladder and bowel dysfunction;
- pressure sores arising from immobility in spinal cord injured;
- dysphagia presenting with swallowing disorders such that the person loses the enjoyment of eating or is at risk of aspiration pneumonia and malnutrition;
- neurogenic pain syndrome
- communication difficulties;
- sexuality and sexual dysfunction;
- mood, behaviour and personality changes;
- changes to family dynamics, personal relationships, career opportunities and financial security.

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Rehabilitation medicine specialists work exclusively in rehabilitation medicine and their work is not compromised by the demands of acute medical care. Patients with acute major disabling physical conditions and particularly those with complex needs, require attention from a multi-professional team led by a specialist in rehabilitation medicine.

Rehabilitation medicine specialists continue to be involved with follow-up of patients as they re-enter living in the community with the target of:

- preventing secondary health problems and social isolation;
- preventing carers becoming exhausted by the burden of care leading to the breakdown of domestic support;
- reducing the likelihood of emergency readmission to hospital;
- reducing the likelihood of unnecessary placements in residential or nursing home care;
- avoiding the inappropriate or untimely prescription of disability equipment.

In the acute hospital, transfer of care to the rehabilitation medicine specialist should ideally take place when the emphasis is on rehabilitation rather than resuscitation or acute medical/surgical treatment. Close co-operation between medical specialties is typically required for specialised rehabilitation for several impairments and their consequent functional losses have to be addressed. The transfer of patients to rehabilitation is more usual by surgical rather than medical specialties; e.g. orthopaedics to spinal rehab, neurosurgery to ABI rehab and vascular surgery to amputee rehab, although this pattern may be changing.

Rehabilitation is a multi-professional activity which depends on good communication between staff and the individual skills of the multi-professional team. The team must have clear rehabilitation objectives for the patient and the patient and his/her significant others are full participants in the process.

After a neurological insult, some patients recover spontaneously, and early rehabilitation intervention could lead to a false impression that the rehabilitation treatment has led to the recovery. On the other hand, for many, lack of access to rehabilitation will reduce the likelihood of achieving independence and quality of life. The focus of rehabilitation is to enable people with disabilities to lead the life that they would wish given any unavoidable restrictions imposed on their activities by impairments resulting from illness or injury.

(This submission has been largely based on: Gutenbrunner, C; Ward, A B; Chamberlain, A, 2006. 'White book on physical and rehabilitation medicine in Europe'. *Journal of Rehabilitation Medicine*. 39 [45]:1-48.

### **The role of the general practitioner**

Dr Edward O' Sullivan, Clinical Director, Headache/ Migraine Clinic  
Cork University Hospital (CUH), and GP in Cork City.

In Ireland, we have approximately 23 practising clinical neurologists. This figure represents a slight improvement in services over the past few years but still falls far short of the recommended one neurologist per 100,000 of the population. The lack of provision of services has clear implications for general practice and its capability in accessing neurological services for both acute and chronic conditions. There are two neurosurgical centres, one in the Beaumont Hospital and the other in CUH with a complement of 10 neurosurgeons.

### **Acute services**

The access to acute neurology and neurosurgical services such as general medical and general surgical is generally via the emergency departments of hospitals. Due to the shortage of acute hospital beds, a general practitioner (GP) is seldom able to admit a patient directly to the wards without the patient first being assessed in the emergency department. The criticism here is a lack of capacity within the system to cope with the sheer volume of cases, and these issues have been documented and highlighted for many years through many different forums.

It is against this background that neurological and neurosurgical services strive towards maintaining acute services in a climate where there is an ever increasing demand and need for the specialisation of these services. In order to maximise existing resources I would recommend clear pathways of referral to these services whereby GPs can liaise directly and quickly with the acute on-call neurological and neurosurgical teams thereby avoiding delays in diagnosis and providing early intervention. Modern medicine is achieving better outcomes with early intervention particularly in the management of the acute stroke with thrombolytic agents. To identify those patients who are suitable for thrombolytic therapy, patients need to be referred directly by GPs as early as possible to a unit which has an early intervention protocol. These stroke units are staffed by neurologists, geriatricians, neuroradiologists, speech therapists, physiotherapists and specialist nurses. These multidisciplinary teams are

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standard practice in centres of excellence in neuroscience centres across Europe and North America. The need for funding from the HSE to develop these services should be standardised so that patients who develop an acute stroke, whether in a large urban location or a remote rural area, should have the same access to high quality care within their regional location. This strategy will also require a pathway of referral from hospitals without designated stroke units to those specialist units as outlined above.

### **Chronic neurological disorders**

Neurology is a challenging clinical specialty and neurological disorders frequently present with a symptom complex that is often subtle at initial presentation when the symptoms are early in their evolution. Due to the lack of neurologists in Ireland, GP access to an outpatient appointment is getting increasingly difficult and waiting lists are getting longer. This unfortunately leads to delays in diagnosis, and a suboptimum management of these disorders, many of which are progressive with varying and significant degrees of disability and impact. There is no substitute to the expertise, experience, advice and management that neurologists have to offer, and this specialist advice is at its most important during the initial consultations when investigations are interpreted, a diagnosis is made and a treatment plan is adopted.

Primary care has an important potential role in the on-going management of neurological disorders, and primary care teams have been identified by the HSE as the way forward in freeing up scarce and limited resources within the health care system. These teams will help facilitate a less frequent need to attend a neurology outpatients' clinic after a patient has been diagnosed and his or her treatment initiated. A pathway for discharging some patients back into the community can be achieved, and this is where many of their health needs can be best met. This ultimately creates more capacity within the neurology departments for more patients to be seen. This is dependent upon adequate resources being provided within the community to meet a patient's many health care needs. Primary care teams are multidisciplinary, and team members include:

- GP
- physiotherapist
- speech therapist
- occupational therapist
- rehabilitation specialist
- public health nurse.

At present a GP has very limited access for public patients to these support services, and this unavoidably leads to further appointments with a consultant in order to gain access to basic requirements such as physiotherapy or speech therapy. It is clearly self-evident that this is not the optimum use of a consultant's time in an already overstretched and under-resourced specialty. In addition, the need for patients to travel great distances, often with a family member to large hospitals where parking facilities etc. are inadequate, in order to attend a speech therapist or physiotherapist is clearly an outdated model for the delivery of front-line services. This service model adds to the patient's stress and the inconvenience frequently results in the patient not attending for treatments which are essential to their ongoing care and management. The need for these services to be located in the community with direct GP access is paramount to any advances that can be achieved through re-configuration. It is important to emphasise that this envisaged model is not an alternative to the urgent requirement for more neurologists in Ireland. It will, however, help to maximise as they currently exist the neurological and neurosurgical services in Ireland.

GPs are well trained and are now working in partnership via the primary care team model to manage chronic disease in the community. In the management of chronic and progressive neurological disorders the GP is the ideal person to lead the primary care team, and in partnership with the neurological services can streamline the management of these patients into the future. Easy pathways of re-referral are met with stipulated guidelines and direct access to neurological or neurosurgical teams. Continuing medical education will address the GP's requirements for remaining skilled in the advances and therapeutic breakthroughs of these disorders. It is a GP's greatest frustration to have to refer a patient to a neurologist just to access physiotherapy or radiological neuroimaging. It is also not fair, equitable or acceptable that the neurology services are used in this fashion for this purpose.

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## **The role of the neuropsychologist**

Dr Niall Pender, Principal Clinical Neuropsychologist/Head of Department of Psychology, Beaumont Hospital, Dublin

Neuropsychology is a branch of professional psychology that involves the relationship between brain function or dysfunction and thoughts, behaviour and emotional states. Clinical neuropsychologists use this knowledge in the assessment, diagnosis, treatment and/or rehabilitation of patients across the lifespan with neurological, medical, neurodevelopmental and psychiatric conditions, as well as other cognitive and learning disorders. Neuropsychologists use psychological, neurological, cognitive, behavioural, and physiological principles, techniques and tests to evaluate patients' neurocognitive, behavioural, and emotional strengths and weaknesses (Editorial board, *The Clinical Neurologist*, 1989).

Neurological illnesses or injuries have direct and startling consequences on thinking, behaviour and emotional states. For example, following even mild head injuries people notice alterations in concentration and memory as well as changes in temperament and mood whereas more severe injuries are associated with a disabling constellation of cognitive, behavioural and personality changes. Early signs of dementia can include changes in memory, language and personality, which slowly change over time, and families are often directly affected by these changes. Children with birth or developmental conditions, as well as childhood injuries, must struggle in school and with friendships. These changes are the functional and behavioural consequences of brain injuries and illnesses, and they affect not just the person themselves but their families and the wider social community.

Such difficulties should be managed within a modern health care system, and in the absence of appropriate services these injuries and disabilities can have a significant social and economic cost. As a result of these difficulties people with brain injuries struggle with relationships, studying and working. Many often leave employment, and marriages, sadly, fail. Many of these difficulties could be avoided, and improvements in the quality of their lives made if the patients received timely care from the appropriate professionals. In this case, patients require clear assessments of need and ability, appropriately formulated management plans and efficient follow-up by a discipline specialised in cognition, behaviour and emotion.

Neuropsychology in Ireland, while well-established as a discipline, is still relatively small and underfunded. In 2009, the first division of neuropsychology of the Psychological Society of Ireland was established with a role in training and practice standards. However, access to neuropsychology for patients is still haphazard and variable across the country. Access to acute neuropsychology services is limited and far short of international standards, which suggest that neuropsychologists should be linked with all neurology/neurosurgery services. There are still less than 20 fully trained and employed clinical neuropsychologists practising in Ireland. This is wholly unsatisfactory as there are many young psychologists with a keen interest in neurological illnesses or injuries that are going abroad to train. They eventually remain overseas as no places are available for them to work in Ireland. Similarly, because the HSE does not have a designation for 'neuropsychologists', overseas neuropsychologists who are very well-trained and experienced cannot work in Ireland. This leaves our own patients vulnerable and missing out on appropriate standards of care and treatment.

### **Assessments of need and management**

Neuropsychologists are regularly involved in needs assessments and use high quality standardised psychometric tools alongside detailed interviews and examinations to evaluate an individual's strengths and weaknesses. These data are often used to develop management plans and/or interventions. In many cases the neuropsychologist liaises with local agencies to advise on management and intervention for behavioural, emotional and cognitive difficulties. Neuropsychologists generally spend up to five hours on an assessment between examination, scoring and preparing findings, and this time can significantly benefit patient care. Neuropsychologists are also heavily involved in dementia diagnoses, assessments of need in traumatic brain injuries, brain tumours and other neurodegenerative conditions. They are increasingly involved in the assessment of decision making and aspects of mental capacity for the courts or in relation to treatment and care.

In many other countries the neuropsychologist works closely with a multidisciplinary team to formulate management plans for patients with neurological illnesses or injuries. In Ireland due to the acute shortage of neuropsychologists, there are significant pressures on neuropsychology services and long waiting times, which have also minimised the degree to which neuropsychologists can work within team settings.

### **Challenges for the future**

Neuropsychology is a valuable and evidence-based discipline with a strong international presence. It is a branch of psychology, and therefore has at its heart the interaction between the patient and his or her illness or injuries. There is, as yet, no formal training course for neuropsychology in Ireland but many psychologists train overseas and are keen to return to Ireland with high level expertise and knowledge. The challenge for the future will be to meet this need and to ensure that all patients who require (and could benefit from) the services of a neuropsychologist will have quick and equitable access based on their level of need.



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## **The role of the neurologist**

**Dr Peter Boers, Consultant Neurologist, Mid-Western Regional Hospital, Limerick**

A consultant neurologist is a physician who is trained in the diagnosis and management of disorders of the brain, spinal cord, nerves and muscles. In Ireland, training as a neurologist commences at least two years after graduation from medical school, after the basic intern and senior house officer years, and the membership examination (from the Royal College of Physicians in Ireland or the UK), has been successfully completed. There are many different pathways that a doctor can follow before final qualification as a neurologist, but the basic requirement in Ireland is a minimum of five years of higher medical training in the neurology programme. This involves working in a number of hospitals under the supervision of different neurologists, looking after ward inpatients and working in outpatient clinics in a variety of hospitals and subspecialty areas. Trainees are encouraged to undertake a period of research (either clinical or laboratory), and also to spend some time in overseas posts to broaden their experience. In my own case, I took up my first permanent post as a consultant neurologist in Australia eleven and half years after graduating from medical school (taking into account basic and advanced clinical training, a research degree, clinical neurophysiology training and a fellowship in the UK).

Neurologists play a key role in diagnosing patients with neurological problems. There is a very broad spectrum of neurological illness; some disorders are common, others are rare. Some conditions are benign and self-limiting, whereas others may be recurrent, progressive, disabling or fatal. Neurologists are trained to assess the seriousness or significance of a person's symptoms or complaints. They examine a person to help decide which part of the nervous system is affected by the problem, and how significant this dysfunction may be. Some symptoms may appear to be very alarming, and yet represent a benign problem, or one which is easy to treat. Conversely, some symptoms are markers for serious underlying problems which require prompt assessment and diagnosis.

An important part of the diagnostic process is deciding which tests or investigations may, or may not, be needed. There have been major advances in the number and complexity of diagnostic resources available to doctors, including advances in imaging (such as MRI and nuclear scanning) and blood tests for genetic disorders. Neurologists are trained first to assess whether or not someone needs diagnostic testing in the first place, and if so, which tests are the most appropriate, and will give the best information to help understand or diagnose the patient's problem.

Neurology used to be thought of as primarily a diagnostic specialty; neurologists would come up with a clever or obscure diagnosis, but not have much involvement in therapy or other management. Fortunately, this approach has changed significantly, as there have been great advances in therapy for neurological problems. Some examples are: thrombolysis for acute stroke; new anti-epileptic and anti-migraine medications; injection and infusion treatments for multiple sclerosis, and surgical or stimulation procedures for epilepsy and Parkinson's disease. Neurologists are trained in the initiation and monitoring of these treatments – deciding who needs treatment, when medications need to be adjusted or changed, and also importantly when to stop.

## **Being part of a team**

Significantly, neurologists do not work in isolation – they are part of a team. It is important that GPs are kept informed and involved in the care of their patients with neurological disorders. Treating patients with neurological problems does not just mean medication. Patients require information, explanation and support from patient support groups and specialist nurses, assessment and treatment from a variety of therapist services, as well as social worker and psychology input. Most people with neurological problems will require one or more of these services at some time during the course of their illness. Neurologists help co-ordinate referrals and care, and need a team to assist with this. It is this requirement for a variety of other practitioners and therapists (the team) that makes it difficult for neurologists to work in isolation. In these cases, patients often do not get to see the appropriate therapists, or there may be a significant delay in assessment and treatment by a therapist who is located some distance away from the hospital or the patient. Neurologists also liaise with a variety of other consultants from different specialty areas to help optimise the assessment and treatment of patients.

Most patients with neurological disorders can be managed on an outpatient basis, but some access to hospital is needed for day procedures (such as lumbar puncture, spinal tap or muscle biopsy) and treatments (such as infusion therapies). However, some patients require admission, or are seen while in hospital for other reasons. Looking after inpatients is an important component of the work of a neurologist, who either looks after patients directly under his or her care or advises colleagues on the most appropriate investigations and management. In order to effectively look after inpatients with neurological problems, a neurologist needs the support of a team, consisting of junior medical, allied health and nursing staff. This ensures that the patients get assessed, investigated and treated as efficiently as possible, with the aim of treating their problem quickly and minimising the length of time they need to stay in hospital.

The neurologist is specially trained in the diagnosis and ongoing management of patients with neurological problems. Sometimes patients are seen once or twice, and never need to see a neurologist again, or only infrequently. In other cases, patients may need to be followed up for a long time, sometimes for many years. It is important that patients who require the input of a neurologist are able to access these services as effectively and efficiently as possible. They should also have ready access to the variety of diagnostic procedures and therapies that may be required, which will help in the treatment and management of their neurological condition.

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## **The role of the advanced nurse practitioner in neurological services**

Imelda Noone, Advanced Nurse Practitioner in Stroke Care,  
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### **Introduction**

The roles of the clinical nurse specialist and advanced nurse practitioner have developed significantly in Ireland since An Bord Altranais (Irish Nursing Board) published its Report of the Commission on Nursing: A Blueprint for the Future (1998). This report was the result of collaborative work among those involved in nursing in Ireland. It recommended the establishment of clinical career pathways, which would allow a nurse with extensive experience and advanced expertise, as well as formal post registration training, to be recognised as a clinical nurse specialist (CNS). Further advancement along this pathway could possibly enable the nurse to progress to an advanced practitioner grade (ANP). In this essay, I will concentrate on outlining the work of an ANP in the field of neurology. Denise Cunningham will then outline her own work as a CNS in epilepsy services. Both essays highlight the central role these nursing posts play in placing the person with a neurological condition at the centre, building the service around that person's need, and guiding, enhancing and integrating his or her journey through the health system.

A CNS practises in a defined area, which requires application of specially focused knowledge and skills. Such skills are in demand and required to improve the quality of patient or client care. The specialist practice encompasses a major clinical focus, which comprises assessment, planning, delivery and evaluation of care given to patients or clients and their families in hospital, community and outpatient settings. The specialist nurse works closely with medical and paramedical staff and may make alterations in prescribed clinical options along agreed protocol-driven guidelines. The specialist also participates in nursing research and audit, and acts as a consultant in education and clinical practice to nursing colleagues and the wider multidisciplinary team. The development of the post must be based on service need, and should reflect epidemiological and demographic trends within the region. The core concepts of specialist nursing include clinical focus, patient advocacy, education, training, research and consultancy.

The ANP is an autonomous practitioner, who is highly experienced in clinical practice, promotes wellness, offers health care interventions and advocates healthy lifestyle choices for patients or clients, their families and carers. The ANP works in collaboration with other health care professionals, in accordance with the agreed scope of practice guidelines. The ANP utilises advanced clinical nursing knowledge and critical thinking skills to independently provide optimum patient or client care through caseload management of acute or chronic illness. The core concepts include autonomy in clinical practice, expert practice, professional and clinical leadership and research.

### **The role of the ANP in stroke care**

I am the first ANP in stroke care in Ireland and am based at St Vincent's University Hospital (SVUH), Dublin, which is the main hospital in south-east Dublin, providing acute hospital services for over 350,000 persons. Approximately 10,000 people experience a stroke each year in Ireland (ESRI, 2007) and it is estimated that over 30,000 people in Ireland are survivors of stroke. SVUH admits 250-300 strokes per year of which 90 per cent are over the age of 65 years (46 per cent are over the age of 80 years). The burden of stroke is predicted to increase in the years ahead because of the rapid rise in the elderly population.

The role of ANP in stroke care includes: holistic assessment and management of the patient with stroke under agreed protocols; communicating with patients and their families as early as possible in order to enhance both their understanding of the disease process and subsequent care; providing patient education on stroke, and ensuring secondary prevention measures are implemented.

The ANP works as part of a multidisciplinary team and liaises closely with all members of that team. The ANP also participates in educating nursing staff and other health care professionals through role modelling, mentoring and facilitating the exchange of knowledge at the bedside, in the classroom and to the wider community. A typical working day starts at 7.30am by visiting the A&E department with the consultant physician and the medical team where all patients over the age of 65 years admitted with a diagnosis of stroke in the previous 24 hours are assessed. This early involvement ensures a comprehensive assessment of the patient and direct liaison with his or her family enabling accurate patient history and any other relevant information. As stroke can be such a devastating, disabling disease, the ANP tries to meet patients and their relatives as early and as often as possible to answer any questions they may have.

Stroke patients who are discharged home are followed up by the ANP and the consultant physician in the outpatients department to ensure appropriate secondary prevention and to arrange any further rehabilitation at a day hospital or on a community basis. A recent development is the establishment of a 'stroke prevention clinic', which is run once weekly by both the ANP and CNS. The role also involves the co-ordination of the transient ischaemic attack (TIA) clinic, which is a once weekly outpatients' clinic for TIA patients seen in A&E and who do not require immediate admission.

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A core element of the role is research and audit, an example of which was my participation in a national audit of stroke services in 2006, which was commissioned by the Irish Heart Foundation, in association with the Department of Health and Children. This was one of the largest studies of stroke ever to take place in Ireland and the results of this study informed a much-needed national strategy on stroke care.

### **The role of the clinical nurse specialist in epilepsy services**

Denise Cunningham, CNS in epilepsy, Brainwave The Irish Epilepsy Association

The CNS in epilepsy services works with consultant neurologists, neurology registrars and the multidisciplinary team. The CNS plays a pivotal role in assessment, planning, implementation, evaluation of services and documentation of epilepsy care provided.

Specifically the role of the CNS in epilepsy services involves:

- liaising with the multidisciplinary neurology team to provide an effective, safe and efficient patient-focused service for patients with a diagnosis of epilepsy;
- providing a specialist nursing service for those who have a diagnosis of epilepsy;
- promoting and maintaining a high standard of specialised nursing care in order to ensure the holistic needs of these patients;
- promoting the focus of care on prevention of seizures and maintenance of a good quality of life;
- liaising and consulting with the neurology team regarding inpatient and outpatient care for patients with a diagnosis of epilepsy;
- accepting referrals within the neurology team and developing appropriate therapeutic programmes within her scope of practice;
- encouraging people with epilepsy to manage their own care independently and assist with compliance;
- providing education to people with epilepsy, their families and carers, about epilepsy and treatment. (This is within AMNCH and also includes people with epilepsy within Brainwave services and nationally who require education, support and guidance);
- accepting referrals directly from the GP services for patients currently under the care of the consultant neurologist. (All patients are reviewed by the consultant in the outpatients department initially prior to referral to the clinical nurse specialist in epilepsy services);
- supporting the patient both emotionally and psychologically through the advice, support and guidance of patient support groups and the availability of other self help opportunities in addressing their needs regarding their diagnosis;
- actively promoting the co-ordination of care for patients between the hospital and community;
- providing a telephone advice service to patients;
- operating an epilepsy advice line at Brainwave on Monday and Wednesday mornings from 9.30-1pm;
- providing a nursing resource service on all aspects of epilepsy to staff at AMNCH, which includes pre-registration nursing students, registered nursing staff, allied health professionals and medical staff;
- acting as an effective resource and support for Brainwave staff, including community resource officers and programme manager for the Training for Success course;
- participating in outreach activities including educational presentations, workshops and conferences. This involves delivering presentations to health professionals, people with epilepsy and community groups, which would include schools, colleges and residential settings;
- attending the epilepsy clinics and acting as a direct interface between the hospital and community based services;
- acting as an effective liaison person between people with epilepsy and their families and hospital and Brainwave services;
- acting as the patient's advocate when necessary, especially in an informed discussion to promote the patient's participation in decision making, thereby enabling informed choice of treatment options;
- facilitating and promoting effective communication between medical staff, nursing staff, allied health professionals, other hospital staff, Brainwave, the community, people with epilepsy and their families;
- being involved in continuous audit of current epilepsy practice and evaluation of the service in order to identify where improvements may be made.

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## Patient encounters

When educating a person with epilepsy, a typical patient encounter would involve dissemination of information in a number of areas, including treatment advice, information support and pregnancy information. The CNS in epilepsy services provides treatment advice, information and support specific to patients' needs, presentation, aetiology, medication and management plans. In clients undergoing treatment changes, information may relate to: anti-epileptic drug (AED) side effects or seizures and their management; interactions between AEDs or newly prescribed medication and AED; advice when medication is missed; appropriate travel related advice, and supplements and complimentary therapies. Advice is also given to GPs and patients or relatives in the emergency use and doses of benzodiazepines for serial seizures and status epilepticus.

Information for newly diagnosed clients and those with compliance difficulties includes: the common cause of epilepsy; different seizure types, their presentation and documentation; exacerbating factors; imaging EEG procedures, findings and their significance; first aid for seizures; safety precautions and driving regulations. Explanations about the principles of treatment, prognosis in relation to syndrome, treatment options, drug doses and formulations, the therapeutic dose range, drug half-life serum levels, the mechanisms of action of AEDs, potential side effects and their management, is given.

Women who become pregnant, and women contemplating pregnancy and their partners, are advised about risk of seizures and AEDs to the unborn child, the effect pregnancy may have on the epilepsy and the management of epilepsy during pregnancy. This includes: the teratogenic affects of AEDs; folate supplementation and rationalisation of therapy to minimise congenital abnormalities; the increased potential for haemorrhagic disease in the newborn in women taking enzyme-inducing AEDs and Vitamin K supplementation; breast-feeding; the genetic inheritance of epilepsy in offspring; safety advice in relation to caring for the new-born, and information about the Republic of Ireland Epilepsy and Pregnancy Register at Beaumont Hospital, Dublin.

A person with epilepsy faces a whole range of clinical uncertainties - over the diagnosis, over whether and when seizures will occur, over the nature of seizures and how best they can be controlled and over whether or not they will ultimately remit. Living with a diagnosis of epilepsy involves managing that clinical uncertainty by balancing available options and possible choices, including over the matter of treatment. The unpredictability of the nature and course of epilepsy is a key factor that impacts on the quality of life of people who develop it. Just as it is essential to have a clinician who is a specialist in epilepsy, having a CNS in epilepsy can enhance the quality of life for patients and give more of a patient-centred approach to their care.

## Conclusion: The importance of multidisciplinary care in the management of neurological conditions

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### Multidisciplinary care for neurological conditions

Concerns for the continuity and co-ordination of care in care specialties has emerged since the 1980s, reflecting the increased complexity of managing long-term conditions, including those that are neurological. Continuity is seen as the delivery of services by different professionals within services in a coherent, logical and timely manner. The co-ordination and implementation of care in this format is referred to as multidisciplinary care.

Multidisciplinary service provision in neurology care has been found to be more effective in terms of maintaining quality of life and promoting independence for care users when compared to care that is not co-ordinated and/or does not include a specific skill mix of health care professionals. Some of the most common neurological conditions are progressive in nature and their disease trajectory has necessitated a shift from impairment only to a view that considers the impact of neurological impairment on service user wellbeing. Professional care for service users with neurological conditions consists therefore of a mix of skilled professionals including neurologists, psychologists, psychiatrists, GPs, social workers, speech and language therapists, physiotherapists, occupational therapists, specialist and non-specialist nurses, and nutritionists. The term 'allied health care professional' is used to denote non-medical care professionals.

Though access is means tested in the Irish public health care sector for primary care services, co-ordinated multidisciplinary health care is provided by the HSE. Health care professionals in neurology care work in both the hospital and primary care sector to promote continuity of care between sectors. Their roles are diverse though their common aim is to improve quality of life for service users. The health care professionals involved in neurology care include the following:

- the neurologist, who is responsible for the clinical diagnosis and decisions on clinical management;
- the GP, who provides medical management to the service user in the primary care sector and is the gate keeper between primary care and secondary and/ or tertiary hospital sector;

- the psychiatrist, who is responsible for the assessment and treatment of the service user for psychiatric manifestations associated with neurological disorders;
- the psychologist, who is primarily responsible for providing psychological support to the service user. (Neuropsychologists are specifically responsible for the assessment and treatment of neuro-cognitive problems arising from neurological damage);
- the clinical nurse specialist, who interfaces between the service user and the health care system and assists in the co-ordination of care provided by all health care professionals;
- the physiotherapist, who assesses the physical changes that occur from neurological damage and is responsible for the treatment of mobility, muscle and joint integrity, and fitness;
- the occupational therapist, who assesses levels of function in activities of daily living and provides treatment modalities i.e. education, aids and equipment, life management strategies and work simplification, to promote independence;
- the speech and language therapist, who is responsible for the assessment of both communication and swallowing disorders arising from neurological impairment;
- the dietician or nutritionist, who is responsible for the assessment of a person's nutritional status, advises on supplementation feeding as required and/or modifications to diet;
- the social worker, who provides advice and guidance on health care entitlements and resources, financial matters relating to care, and counselling services to assist in coping with changing life circumstances.

### **Providing multidisciplinary care for people with neurological conditions in Ireland**

Irish health care services have long been recognised as under-resourced and under-developed to meet the demands of people with neurological conditions. While there are potential benefits of multidisciplinary care in terms of cost effectiveness and user satisfaction, waiting lists for care intervention across services remain extensive. There are a number of problems in multidisciplinary neurology care which challenge service delivery. Extensive waiting times exist between initial neurological presentation and formal diagnosis caused by too few neurologists and slow access to diagnostic tools and techniques in the diagnostic phase. Despite the important role of allied health care professionals as outlined in managing lifelong adjustments to neurological impairment, limitations exist across allied health care services both in numbers, diversity and skill mix. Though there has been a consistent lack of government funding and commitment to allied health care services, the challenges found within multidisciplinary care provision are not only financial but also a product of paradoxical and poorly planned strategies for the long-term delivery of services. The slow implementation of primary care teams under the framework suggested by the HSE, i.e. generalist care, is inconsistent with care models that emphasise the importance of allied health professional specialist care services. In addition, while the restructuring of allied health care services within and towards the primary sector is warranted, this community care model is adopted from other recognised health care systems, which are predominantly public oriented and which do not have the mix of public and private finance that is characteristic of the Irish public health care system i.e. National Health Service (UK). Problems exist in relation to who can access public allied health care services in Ireland. Service users without a medical card often encounter problems in the primary care sector and decisions about access to public hospital allied health care professionals are made by respective facilities.

There are opportunities for developing and improving multidisciplinary and allied health care in neurology services. However, a genuine understanding by health care management and government of the role of allied care professionals in assisting those with neurological conditions, beyond specific episodes of illness, is required. Allocation of adequate funding and infrastructure, to prove effectiveness in terms of cost benefit and impact on service user wellbeing, is needed. Those involved in the strategic planning of services need to consider that service users with neurological disorders often require ongoing intervention. Proving the effectiveness of multidisciplinary services may assist service planning. This should also assist service providers to recognise the commonalities but also the differences between primary, secondary and tertiary care and how they can compliment each other to provide services that are both accessible and appropriate for service users.

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## PART II THE OPPORTUNITY

**Chapter 9:** The role of non-statutory organisations in the delivery of services to people with neurological conditions

The Neurological Alliance of Ireland

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“Six years ago, I was in a car crash. I was in a coma for four months. I had to re-learn how to walk, how to talk, and even how to go to the bathroom myself. After a few months, I went home to my family. It was then that things got worse - I tried to live as the man I knew before my accident, but I was like a stranger in my own house. I couldn't go back to work. Eventually, through the service I'm now attending, I re-learned how to read and write. I also learned how to cook and use computers. Going there gives me a reason to get up every morning.”

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## **Chapter 9 - The role of non-statutory organisations in the delivery of services to people with neurological conditions**

### **The Neurological Alliance of Ireland**

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#### **Introduction**

Like most modern democracies, Irish and European society is supported and served by a not-for-profit or voluntary charitable sector, which delivers a range of services to its citizens. The sector in Ireland pre-dates the modern state and has always responded to those in need.

Non-statutory organisations make an important contribution to society through their demonstration of collective action. They exemplify the principle of citizens participating in and taking responsibility for their community and ensure that no government has a monopoly on the way society deals with its citizens, especially those who are vulnerable.

There have been a number of steps in legislating for the role of non-statutory organisations in the provision of health care in Ireland. In 1989, the Commission on Health Funding highlighted the immensely important role of voluntary organisations, referring to their community spirit, humanitarianism and, critically, closeness to the client group. The Health Act in 2004 stipulated that in performing its functions, the HSE “shall regard to ... services provided by voluntary and other bodies that are similar or ancillary to the services the Executive is authorised to provide”. Coupled with this is the recognition of the value of the non-statutory sector by individual health professionals and statutory service providers who depend on working in partnership with these organisations. Surveys of people with neurological conditions continually find high levels of satisfaction with the support they receive from these organisations.

In practice, however, the involvement of non-statutory organisations has often been seen as external or peripheral to the management of neurological conditions within the Irish health services, with non-statutory organisations viewed as additional rather than intrinsic to health service delivery.

This chapter will outline the integral involvement of non-statutory organisations in the management of neurological conditions in Ireland. They do this through direct provision of services in response to unmet needs, facilitating service users in accessing services and managing their condition, and providing a focus for the development of policy, research and expertise in the needs of people with neurological conditions. It will point to the contribution of non-statutory organisations in providing a framework for community-based health care provision in line with the vision of the HSE Transformation Programme and the Primary Care Strategy. Integrating the expertise and experience of non-statutory organisations into a strategic vision for neurological care in this country represents a significant opportunity for our health service going forward.

#### **Non-statutory organisations: A response to the unique needs of people with neurological conditions**

People with neurological conditions have particular needs within a health service framework, which non-statutory organisations are uniquely positioned to address. These complex conditions have a wide range of physical, intellectual, social and emotional consequences for the individual and their family. Coming to terms with and understanding the sudden onset or diagnosis of a neurological condition and adapting to the consequences over time requires a range of personalised supports, which are essential to an integrated response to health care, but typically lie outside the remit of general health services.

Providing a long-term, co-ordinated response to the needs of people with neurological conditions is traditionally very difficult for the health services due to age-related boundaries in service provision and difficulty in co-ordinating care across different health care settings, often in different geographical locations. Non-statutory organisations are in a unique position to provide this continuity through a flexible, person centred approach which can support the individual and their family in accessing the services and supports they require.

#### **Meeting the need: Services provided by non-statutory organisations**

Non-statutory organisations have been at the forefront in developing flexible, innovative responses to the needs of people with neurological conditions, closely involving service users in the design and delivery of supports. This section outlines some of the wide range of services developed by these organisations, along with an illustrative example in each case.



Services include:

- *provision of specialist information and advice to people with neurological conditions;*
- *training and support for staff working in a range of health care settings;*
- *provision of home and community services, including home based supports, residential services, respite services and day services;*
- *community rehabilitation services;*
- *development of clinical specialists;*
- *acting as consultative partners in developing responses to the management of neurological conditions;*
- *facilitating access to health services for people with complex long-term care needs;*
- *supporting self management of neurological conditions;*
- *training and support for family members;*
- *promoting, commissioning and supporting research into neurological conditions;*
- *developing and supporting innovation within the health services.*

(Note: The examples provided are intended to demonstrate initiatives by Neurological Alliance of Ireland (NAI) member groups in each of the service areas outlined. It is important to note that these examples represent only one aspect of a wide range of services provided by these individual organisations.)

## **The range of services provided by non-statutory organisations with examples of specific initiatives**

### *1. Provision of specialist information and advice to people with neurological conditions and their families*

Non-statutory organisations have developed a range of flexible approaches to respond to particular requirements in the communication of advice and information to people with neurological conditions and their families: Information and advice are available in a person centred format which is particularly important in order to provide time to understand and come to terms with the range of consequences and complex management of neurological conditions;

- Information services are easily and directly accessible, often through a helpline service;
- Non-statutory organisations often provide detailed information on locally available services and supports enabling people to access health services to meet their needs;
- Non-statutory organisations provide a single point of contact allowing them to respond to the individual needs and experiences of their clients over time.

#### **Specialist Information Services: Migraine Association of Ireland website**

Founded in 1994, the Migraine Association of Ireland (MAI) has now grown to become an organisation, which is recognised as one of Europe's leading headache patient associations. The Association seeks to empower and optimise the quality of life of people with migraine or other headache disorders.

MAI provides information, support and advice to health professionals and migraineurs on a range of migraine issues. One of the primary ways it does this is through its website, which won an award at the Irish health care awards ceremony for 'Best Use of Information and Technology'. The website provides the most up-to-date information on migraine to aid health professionals make accurate diagnosis, prescribe appropriate medications and provide the best possible treatment practices. Numerous resources and links are available to download for both health professionals and their patients, which help people manage their migraine and, in doing so, reduce the enormous impact migraine can have on their lives.

To mark Migraine Action Week 2009, the MAI recorded a number podcasts to form a self-help series. From personal stories to relaxation exercises to tips from its migraine specialist nurse, these podcasts are also designed to increase knowledge of migraine among health professionals and help people better understand issues related to their migraine.

Source: MAI Website

## *2. Training and support for staff working in a range of health care settings.*

Non-statutory organisations provide comprehensive information, which has been developed in partnership with specialist health professionals and plays a vital role in disseminating information on these conditions to staff working in a range of general health care settings, many of whom rely on information leaflets and websites as well as training seminars and conference provided by non-statutory organisations to develop their understanding of the complex needs of people with neurological conditions.

### **Training and Support for Healthcare Staff: Post Polio Support Group Information Guide**

The Post Polio Support Group has developed a guide to the treatment of post polio syndrome in primary care. This initiative was undertaken by the organisation in response to the need to ensure that polio survivors receive the best possible care and treatment at primary level – through effective intervention and support at this stage, many polio survivors can remain independent and within their homes and communities. The guide was developed with the support of the HSE. The aim of the publication is to inform health professionals working in primary care and to place them at the leading edge of service delivery to those experiencing post polio syndrome. The book *Post Polio Syndrome - Management and Treatment in Primary Care* focuses on the provision of effective primary care to polio survivors, and contains up-to-date information on most aspects of the care requirements of the thousands of Irish people displaying the symptoms of post polio syndrome.

## *3. Non-statutory organisations as providers of home and community services*

Non-statutory organisations have been the main drivers and providers of community based, personal support services. While models of services have evolved over the years, organisations continuously strive to deliver person centred, flexible, quality services, which aim to provide people with neurological conditions with the appropriate supports to enable them to live as independently as possible within their own communities.

A wide range of services are available and include:

- home-based services such as home help, home support, personal assistant services;
- respite services, which provide those with disabilities and their carers with the opportunities to take a break either in a dedicated respite centre or at home;
- supporting people to live in their own homes through assisted living or supported accommodation services;
- opportunities for socialisation, therapeutic or rehabilitative intervention, education, personal care and leisure activities, which are available in day services, resource centres and social clubs.

### **Home Support Services: RehabCare's Carelink Home Support Services**

RehabCare's home-based services are provided under the brand name CareLink. CareLink provides a range of support services, which enable people with disabilities, including people with neurological conditions, to continue living in their own homes with appropriate support and assistance from trained home support workers. Services are specifically tailored to meet the individual needs of clients who require support and assistance with activities of daily living such as domestic tasks, personal care, community participation and social and leisure activities. CareLink services are renowned for their flexibility, ensuring that the needs of service users are fully taken into account at all times, including unsociable hours and at weekends. They provide the individual with support for all the activities of daily living while they remain in their own homes. This also supports their primary carers by providing temporary assistance in their full-time caring role. CareLink's person-centred approach, flexibility and trained staff ensures its clients receive a quality service which responds to their changing needs over time.

### **Supported living services:** Cheshire Ireland Community Services Dublin/Cork supported accommodation services

In its early years, Cheshire Ireland was set up to provide a home and personal supports to people with physical disabilities and neurological conditions. Most users of the service could not remain living at home because their informal care system had broken down; they were living in hospital wards or inappropriate institutions, or had grown up in residential institutions.

In recent years, Cheshire Ireland has established a process of comprehensive service design and planning that takes place with the person, his or her family and the HSE to assess and identify the person's needs across a whole range of domains. Services are then designed or facilitated to meet the range of requirements. Cheshire Community Services in Dublin delivers support services to people who remain living in their own homes, their family homes or newly acquired homes. The supports include night support, assistance in shopping trips, health appointments, daily domestic tasks, social and leisure activities, advocacy and personal care. The Cork Supported Accommodation Service also provides a range of supports to 10 people, some of whom have substantial support needs, to live in the area and house of their choosing in Cork City and County. Critical to the success of these services is the role of the service co-ordinators. They are not only responsible for the delivery of individualised services, but for ensuring that local HSE and other voluntary agency supports identified during the service design process, are delivered when required. Also vital to this service are the staff members who support people in a way that is person-centred and safe. Cheshire Ireland also provides respite services in a number of locations around the country with two stand-alone services in Newbridge and Shillelagh, Co Wicklow.

### **Respite services:** RehabCare West Cork Respite Service

RehabCare opened West Cork Respite Service in October 2007 following the identification of a gap in services within the area. The respite service caters for a maximum of four people at any one time and can support people with high care needs. The ethos within the service is that people get a service based on social needs, whilst having any medical needs met. As such the service is set up as a home-from-home setting, and every individual chooses what they would like to do during their stay. Each person chooses when and what they want to eat, and where they would like to go out to either during the day or evening. Some of the activities have included going to the cinema, going for a pizza, to hairdressers, beauticians, on walks, visiting museums, going to the pub, fishing and shopping. After each visit everyone is asked what they liked about the service and how it can be improved. Without doubt, the service has supported people to remain in their own homes, and both clients and carers look forward to a break.

### **Day services and social clubs:** Alzheimer Society day services and social clubs

The Alzheimer Society of Ireland provides a network of dementia-specific day care centres throughout Ireland. Based on a social care model and specialist staff training, this vital community service is person-centred, rights-based and provides a warm welcoming environment for people with dementia and their families. Society day care services enhance quality of life and support people with dementia to continue to live at home for longer by:

- providing dementia specific care, therapies and activities which are designed to meet the individual needs of service users, taking account of their wishes, views, preferences and life stories;
- focusing on abilities and sustaining life skills, stimulating people with dementia and providing a social experience that is rewarding for clients and also enhances the caring experience at home;
- providing a vital break to family caregivers as well as access to information and family carer support groups;
- reducing and alleviating the isolation, loneliness and stigma a diagnosis of dementia can bring by providing a social experience and network to both people with dementia and their families.

#### 4. Community rehabilitation services

Many people with neurological conditions either do not have access to, nor need, inpatient rehabilitation. Gaps in the provision of specialist neurorehabilitation services in the community in Ireland have seen non-statutory organisations out of necessity develop a range of services in response to the needs of their clients. These services try to cater for the lifelong needs, beginning with diagnosis or the acquirement of the disability. The model of these services is to assist, encourage and enable people to regain maximum potential in their lives, working towards an agreed set of individualised outcomes with those affected and their families. The settings are centre based, and include such services as day resource services, rehabilitative and vocational training programmes and home-based programmes (such as one-to-one trained rehabilitation assistants working in the home, as well as assisting access to social, educational and vocational aspects in the community).

##### **Community Rehabilitation Services: Headway Community Integration Service**

Following a brain injury, people can easily become isolated in their own community. The Headway Community Integration Service helps people with acquired brain injury (ABI) take part in social and recreational activities, with the specific aim of increasing levels of awareness and confidence to participate. With help from a community integration officer, people choose activities that they have an interest in, for example accessing their local library, going to the gym, going to the cinema, etc. Through real-life practice and with the support of the community integration officer, the service helps people plan and execute strategies to overcome the difficulties they encounter, thereby increasing levels of independence. Eventually, as progress continues, the support from the community integration officer decreases but the person can still contact the service if he or she has any questions, issues or wants to access another activity with support.

As one service user put it: "The programme helped give me the confidence to get back out into society on my own again. I probably wouldn't have been able to do it without the support of Headway."

#### 5. Development of clinical specialists

Non-statutory organisations have recognised the importance of specific health professionals in the management of neurological conditions and the significant shortage of these personnel in Ireland, particularly in the community. One example is the development of neuropsychology services in response to the very low number of these personnel within the health services, or at least only operating within certain inpatient facilities or geographic areas. Availability of specialist personnel within non-statutory organisations allows for increased access to these services for people with neurological conditions. These personnel are most often based in community settings with potential for greater contact and co-operation with statutory health service staff in a wider range of settings. The costs of these posts are frequently borne or supplemented by non-statutory organisations through fundraising.

##### **Development of Clinical Specialists: The Irish Motor Neurone Disease Association Clinical Nurse Specialist**

The Irish Motor Neurone Disease Association employs one dedicated motor neurone disease (MND) nurse specialist. It does not receive any statutory funding for this post, so relies on fundraising activities to provide this position.

The MND nurse specialist provides a vital service to the MND community, as she provides information, advice and supports to people with MND and their families on how to manage the symptoms of the condition. Due to the rapid progression of MND, there are ever changing needs from diagnosis onwards, and the patient and their families need to be fully informed. The MND nurse specialist co-ordinates the care provided by all health care professionals, and liaises between the hospital and community-based services. Because of her unique role, which interfaces between the patient and the health care system, the MND nurse specialist is also a powerful patient advocate. The MND nurse provides home visits as required, and can 'fast track' patients who require urgent community or hospital based services. Many crises can be averted by the timely intervention of the specialist nurse.

Another role the MND nurse specialist plays is that of an educational one; she provides an information and advice service to community health care teams, hospital teams and nursing home staff throughout the country. This information includes an explanation of MND, the symptoms and how it progresses. She provides information to the health care professionals so when they come in contact with people with MND they know what to look out for, and are fully informed of the potential needs the patient will require, as MND can be an unpredictable disease.

## *6. Consultative partners in developing responses to the management of neurological conditions*

There is increasing recognition of the need to consult service users in the development and delivery of health care services. Non-statutory organisations have strong ongoing involvement with individuals with neurological conditions and their families, and have developed their own services in consultation with their members. Through their experience and expertise in working with service users, non-statutory organisations continue to play a vital role in advising on appropriate care pathways and services for the management of specific neurological conditions.

Non-statutory organisations also advise on particular needs of people with neurological conditions in a range of general health care settings, including acute hospitals, nursing homes and residential settings. They also provide a vital source of information, expertise and training for healthcare staff working in primary care, mental health and palliative care services, on the specific needs of people with neurological conditions.

Non-statutory organisations continue to play a key role in generating and directing the development of health policy in order to meet the needs of people with neurological conditions in Ireland. A key example from the National Neurorehabilitation Strategy is outlined below.

### **Consultative Partners:** The NAI working group on neurorehabilitation

The NAI is the representative umbrella group for non-statutory neurological organisations in Ireland. The organisation established a working group on neurorehabilitation in August 2008 to co-ordinate the input of its members to the development of the National Neurorehabilitation Strategy. This working group carried out a service mapping project, producing a unique set of pathways reflecting the experiences of people with specific neurological conditions in Ireland. These "maps" identified key points in the service journey where specific intervention is needed to prevent people falling between gaps in services, or risking loss of function and increased disability at a later stage. The group organised a national conference on neurorehabilitation in association with the Department of Health and Children to provide information to a range of service providers in this area and to focus debate on this issue. The group also provided ongoing material to inform the development of the National Neurorehabilitation Strategy as it progressed.

## *7. Facilitating access to the health services for people with complex long-term care needs*

Ensuring continuity of care and a single point of contact for people with neurological conditions represents a significant challenge for the health services as these people often have a range of complex, long-term care needs which change over time and which involve a number of health professionals and agencies working across different health care settings. Non-statutory organisations play a key role in identifying and advising individuals and their families on the services that are available to them and facilitating access to these services through key worker and case management services. They provide a single point of contact and a co-ordinated response along complex care pathways.

### **Facilitating Access to Health Services:** The Acquired Brain Injury Ireland case management services

The ABI case manager is the key link professional for the individual with an ABI. He or she ensures lines of communication are established between the Social Work department and discharge liaison nurses from the acute hospitals and the National Rehabilitation Hospital, and also facilitates seamless discharges, with gaps in community services identified at an early stage. This ensures discharge with an 'appropriate' and individualised package of care to ensure adequate and suitable supports from the outset, including home support, day services, respite and other relevant therapies. This further ensures adequate support is in place immediately post discharge, which helps to prevent the breakdown of care packages and mitigates against re-admissions to hospital in the future, particularly in complex cases.

Following notification of the ABI to the case manager, support and education to clients and families is initiated. With a case manager involved from the start, both families and the relevant health care professionals know that there is a professional who understands the specific difficulties they are going through at any particular time. By attending the review or discharge meetings in the acute or post acute setting, the case manager is able to bring a sense of realism to the level of service provision that is available to people with an ABI within their own community. Funding needs and service gaps are identified early, which averts unnecessary frustration on the part of the client, family and staff involved, and facilitates the efficient use of services that are already in place.

cont.

In essence, case managers take a holistic, individualised, goal orientated and outcome-based situational approach to how an ABI impacts on an individual's work, family and social life. They provide and facilitate a variety of supports, both direct and indirect, which allows the individual and their family move forward together following an ABI, confident that there will be someone there to support them in meeting the challenges that lie ahead.

### *8. Role of non-statutory organisations in supporting the self management of neurological conditions*

It is increasingly recognised that health services need to focus on informing and training people in the management of certain aspects of their care, particularly in relation to people with long-term chronic conditions. There is evidence of the role of self management in chronic illness in reduced severity of symptoms, improved life control and activity and improved resourcefulness and life satisfaction together with improved communication with health service providers.

Perceived self efficacy in managing aspects of care has an important role to play in improving outcomes in specific neurological conditions (Wassen, 1992). Non-statutory organisations have designed specific programmes aimed at supporting people with neurological conditions in explaining symptoms and managing fatigue, problem solving, accessing health services and communicating with health care professionals.

Non-statutory organisations also provide a range of supports to allow individuals to make informed choices about their care and in identifying and accessing the services they require.

## **Supporting Self Management of Neurological Conditions**

### **The Parkinsons Association of Ireland exercise chart**

In 2007, the Parkinson's Association of Ireland, in association with Lundbeck Ireland, came up with the idea of an exercise chart for people with Parkinson's disease. Gathering momentum on the research front was the growing suspicion that exercise might be very beneficial for people with neurological conditions, and the organisation approached Grainne McKeown, Chartered Physiotherapist, with the Dublin Physiotherapy Clinic with the idea of developing a short series of exercises to assist in maintaining flexibility. One major problem in Parkinson's is that because of the greater effort moving takes, one's range of movement becomes smaller, and this has obvious consequences for ongoing maintenance of flexibility, hence the importance of these exercises. The tendency to stoop is catered for, along with shortening stride - both by stretching exercises. Leg stretches are also good for warding off an imminent leg muscle cramp, common in more advanced Parkinson's. Stretching also helps reduce muscle rigidity.

The result, with the assistance of two people with Parkinson's disease who posed for the illustrations, was a brightly coloured, easily understood fold-up exercise chart. The chart itself was thoughtfully matt-laminated for durability. Three years on, it remains one of the organisation's most popular handouts, and it is also available on its website.

### **BRAINWAVE The Irish Epilepsy Association lifestyle and self-management programme**

Brainwave offers an individualised lifestyle programme for adults with epilepsy, which complements their medical treatment. It explores two main aspects - the need for epilepsy information and lifestyle related support. Goals are identified, as are barriers to following through. It looks at a range of issues; seizure triggers; seizure preparedness; safety; socio-emotional issues, and self care. Awareness of emotions and their impact on behaviour and choices is a significant component. Sessions on stress, communication issues, and handling other people's responses feature in the programme. The objective is to empower the person to become pro-active in reducing triggers and improving wellbeing.

### *9. Training and support for family members*

Non-statutory organisations recognise and support the role of family members as vital partners in the management of neurological conditions and provide a range of specialist training, support, counselling and information services for family carers.

## Family support

### Muscular Dystrophy Ireland (MDI) family support service

Muscular dystrophy is a genetic progressive muscle weakening condition. MDI's family support workers (FSWs) are experts in accessing the specific medical and social supports that adults and children with muscular dystrophy require. Many adults with muscular dystrophy experience social isolation; FSWs can support people to integrate into their community. One adult had not been able to go to out to shop for clothes for over four years until the FSW arranged transport and a personal assistant. He described it as "a day I will never forget", a first step to a more independent life.

The FSW provides practical and emotional support to enable people to cope with the diagnosis and changes in their life due to the progression of the condition. Support extends to family members who may have the condition themselves, carry the gene, are carers or are dealing with bereavement. In MDI's National Survey 2009, one parent said: "You need to have a strong voice to get things done." FSWs ensure that those who may not have a strong voice are not left behind and that everyone with muscular dystrophy has the same opportunity to access the essential services and care they need.

### Carer training

#### Huntington's Disease Association carer workshops

Huntington's disease (HD) is a multifaceted inherited disorder of the central nervous system, which involves changes in behaviour, cognitive decline, involuntary movements and speech impairment. The hereditary nature of HD creates generational hardship within families, often bringing feelings of shame, guilt and social isolation. Cognitive and behavioural difficulties, dementia, and communication problems can lead to aggression and frustration for the person with HD and emotional stress and fear for family members.

Many HD carers face a continuing cycle of caring. In addition to caring for a spouse or partner for many years they may also care for their adult children who inherit HD. Children who care for a parent with HD have to cope with the reality that they themselves (or their siblings) may also develop HD.

HD-affected families are unique and require flexible support and understanding. Carers' workshops allow carers to discuss their problems and anxieties in a safe and understanding environment. The family support officer acts as a facilitator and follows up with those who need one to one support. Many carers find the peer support a source of strength, and learn coping mechanisms from other HD family carers.

## 10. Promoting, commissioning and supporting research into neurological conditions

Non-statutory organisations continue to support research into neurological conditions in Ireland through providing specific research funding initiatives, encouraging their members to participate in research projects, commissioning specific research projects on behalf of their organisations and through research collaborations with health professionals and university departments.

## Promoting, commissioning and supporting research: Dystonia Ireland and Brainwave The Irish Epilepsy Association

### Temporal discrimination threshold as an endophenotype in adult onset primary dystonia.

Dystonia Ireland's current research focuses on how the brain processes information about the timing of events in dystonia. The recent research has shown that individuals without dystonia can typically distinguish two repeated stimuli (e.g. flashing lights) at an interval of 30 milliseconds. Patients with adult onset primary torsion dystonia (AOPTD), however, need at least 60 milliseconds to appreciate two separate stimuli. Furthermore, the researchers have found that approximately half of first degree relatives (parents, siblings or offspring) of patients with AOPTD also need more time to detect such temporal differences (differences in time). This finding is very important because the difficulty in processing temporal information, while not causing any problems in these individuals, may act as the marker of silent gene carriage we need. Dystonia Ireland is currently extending this research in two important ways.

First, the researchers are gathering data on more dystonia patients and their first degree relatives, which will allow them to accurately gauge how common abnormal temporal processing is among these individuals. They are also gathering a genetic profile on these individuals by taking a small amount of blood, which will then be used to examine DNA.

Second, in order to determine what part of the brain is responsible for temporal processing, they record brain activity using two methods, electroencephalography (EEG) and MRI scanning. The research will lead to greater understanding of what is happening in the brain that causes AOPTD, and researchers hope it will contribute to the identification of the genetic cause or causes of AOPTD.

### Brainwave Research

Brainwave The Irish Epilepsy Association is an NAI member group established in 1967 with the aim of improving the quality of life of people with epilepsy in Ireland. Supporting epilepsy research is one of Brainwave's key strategic objectives, and in recent years the charity has become very proactive in supporting a number of Irish projects.

Work to date includes The National Study on Sudden Unexpected Death in Epilepsy (SUDEP) in Ireland, an incidence study underway with University College Hospital Galway and Beaumont Hospital, and the Health Related Quality of Life of Adults with Epilepsy in Ireland study undertaken at University College Dublin (UCD).

Perhaps the most significant piece of work has been the completion of the Prevalence of Epilepsy in Ireland study, the first national epilepsy prevalence study undertaken anywhere in Europe. Conducted by the UCD Centre for Disability Studies, the study identifies for the first time, accurate figures on the number of people with epilepsy in Ireland. It was recently published online in the journal *Epilepsia*.

In 2008, Brainwave established a formal research funding scheme and the first three awards were made in 2009. Two of these are co-funded by the Health Research Board (HRB) under the HRB/ MRCG Joint Funding Scheme.

All three projects, investigating SUDEP, epilepsy pharmacogenomics and temporal lobe epilepsy have the potential to add significantly to existing knowledge and aid in the search for better outcomes for people with epilepsy.

### 11. Developing and supporting innovation within the health services

Non-statutory organisations have been to the forefront in developing innovative approaches to the design and delivery of services for people with neurological conditions. These often include using fundraising and sponsorship to develop creative responses to an unmet need among their client group.

#### **Developing and Supporting Innovation: Getting the Balance Right Programme, Multiple Sclerosis Society of Ireland (MS Ireland)**

In 2006, MS Ireland employed the services of Lansdowne Market Research (now called Millward Brown Lansdowne) to conduct research among its members relating to services for people with MS. The findings clearly highlighted that physiotherapy and exercise-related programmes were the top priority of services required but not widely available either through the HSE or from MS Ireland, due to the current level of resources.

With the need identified MS Ireland, in collaboration with the physiotherapy department at the University of Limerick, developed a programme to respond to this need through physiotherapy and exercise-based interventions and to evaluate their benefits. This two-year project was funded through MS Ireland resources and with assistance from the Dormant Accounts, Pobal.

Entitled Getting the Balance Right, the programme aimed to give people with MS the opportunity to access physiotherapy and exercise-related interventions with greater frequency and intensity at a pace and place suitable to the person's need. It was also an opportunity to profile people's needs and assess the benefit of interventions, allowing MS Ireland to provide and advocate for evidence based service delivery and better services for people with MS.

To date over 1,700 people have taken part in the many varied physiotherapy and exercise related activities such as group and one-to-one physiotherapy, yoga, fitness instructor-led gym classes, tai-chi and hydrotherapy. Each of these interventions was, and continues to be, delivered locally in towns and villages across the country. An evidence based tool kit for physiotherapists has been developed and a very positive collaboration between MS Ireland and the HSE primary care teams in respect of service delivery has been strengthened.



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## **Non-statutory organisations as key partners in community-based health care**

A historic underdevelopment of community-based services for people with neurological conditions in Ireland has led to a reliance on the non-statutory sector to provide such supports. These organisations have developed significant expertise and experience as a result.

Through the development of the HSE Transformation Programme and the Primary Care Strategy, there is increasing emphasis on the need for a community based approach to long term chronic illness. Non-statutory organisations already offer a range of opportunities to work in partnership with other health service providers in the management of neurological conditions in the community through:

- providing a wide range of specialist services in the community for people with neurological conditions;
- providing case management and key worker services to assist people in the transition from hospital to community services and in the long-term management of their condition;
- providing information and training opportunities for staff in a range of community based health care settings.

There is an acknowledged critical requirement to develop community based health services to meet the needs of people with neurological conditions in Ireland. Such development should recognise the key contribution of non-statutory organisations in this area to date and effectively harness their expertise in the design and delivery of future services.

## **Conclusion: Integrating the work of non-statutory organisations; an opportunity for the health services**

This chapter has outlined the importance of non-statutory neurological organisations in meeting the needs of people with neurological conditions in Ireland.

Non-statutory organisations play a key role, not only in the provision of specialist supports not available through general health services, but in supporting the individual in managing their condition, improving their service journey, informing and training staff in a range of health care settings and providing a focus of expertise for policy development, research and innovation.

A critical test for our health system should be its ability to recognise and incorporate the experience and expertise available within non-statutory organisations to deliver efficient and effective neurological care across all areas of health service provision.

The NAI, as the umbrella group representing these organisations, will continue to emphasise their essential role in meeting the needs of people with neurological conditions and their vital contribution to the health service in meeting its duty of care to these individuals and their families.

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## PART II THE OPPORTUNITY

**Chapter 10** - Service delivery for neurology in the context of health service reform – 'Getting from here to there – A practical guide'

Dr Colin Doherty

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"M (herself a person with Parkinson's) says: "I visited a person with Parkinson's disease (PD) in a private nursing home. This person had advanced PD and so there were times when she could only move with great difficulty. I stayed a few hours with this person in her room, and was asked to ring the patient's call button in the room on behalf of the patient, because the medication was late in coming. The room was arranged so that the only chair in it - occupied during the day by the person with D - was across the room from the person's call button. This meant that when she needed help, or to remind the staff to bring her medication (in advanced PD the timing of medication is much more important and you can sometimes go "off" quite fast and be unable to move), she could not reach the call button if "off" at the time!"

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## **Chapter 10 - Service delivery for neurology in the context of health service reform – ‘Getting from here to there – A practical guide’**

**Dr Colin Doherty, Consultant Neurologist, St James’s Hospital, Dublin**

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### **Introduction**

Although they may differ, health systems around the world have a common goal: to improve the health of the population they serve by delivering high quality, accessible and financially sustainable health care. Given ballooning health care costs and increasing demands of consumers, achieving this goal is becoming ever more challenging. Quality, access and sustainability form an elusive triad for most health systems, which struggle with at least one of those dimensions.

As has been pointed out all too often, neurological services in Ireland have suffered historically from chronic under-funding and thus are obliged to address that common goal from a very low base. Nevertheless, the principles of optimal health care delivery are no different.

The goal of this chapter is to outline the questions that need to be addressed in order to deliver a high quality sustainable service for neurological disorders in Ireland. These questions will be discussed within the framework of currently stated goals of health care reform, which have been outlined in various reports over the last number of years.

### **Health care reform and neurology services**

To the extent that certain aspects of Irish health care reform have already been implemented - such as the re-organisation of operational regions of the HSE; the implementation of elements of the primary care strategy; the focus on certain chronic diseases for specific funding initiatives like cancer and cardiovascular disease - this document does not seek to change or introduce radical new elements to health care reform. Instead, this is a practical effort to work within these reforms to make the journey, from where we currently are to where we want to be, as achievable as possible.

I will make certain assumptions in advance:

- health care reform is currently underway and we must take the opportunity that this shift brings;
- whole system change is attractive, but in practice there are many blocks within the supply and demand side of health care that make such a radical change difficult if not impossible;
- the Irish health system is achieving success where it takes a regional approach to health care delivery. ‘Regional’ can be geo-political, population based, patient flow-based or a mixture of all three. Thus, the new operational regions in the HSE offer the first such division. The current infrastructure of the health service, with primary care services, secondary care and tertiary care hospitals, offers a structure for population based reform. Finally, the development of programmes of chronic disease management such as in cancer and cardiovascular disease, reflects the strategy in which patient flow is the determinant of services;
- the final assumption is that there will be, at the end of this process, a model of resource allocation that can support these developments across all sectors. For instance, a model such as Programme Budgeting Marginal Analysis (PBMA) is a system that allows health care leaders create a picture of what proportion of their budget is going on what service. It allows for the creation of ‘wish lists’ and ‘hit lists’ that trade off one opportunity cost for a service gain. Thus, changes are made at the margins of a resource, which essentially keeps the cost neutral.

Once these assumptions are accepted there are five questions, which then determine the development of a regional health strategy for neurological disorders:

1. Why is change necessary?
2. How will the needs of the population grow?
3. What pathways will meet patients’ needs now and in the future?
4. What delivery model should the strategy support?
5. Are proposed changes affordable and sustainable?

#### **1. Why is change necessary?**

Simply put, patients who are living and dying in this country with certain illnesses are not getting anywhere near a basic standard of care. For instance, stroke kills more people in Ireland than breast, bowel and lung cancer put together and yet there has been no investment (until recently) to address this. The reasons for this are complex but largely to do with the health system focusing on ‘total health needs of the community’; thus investing in identified needs and rationing others that do not have a policy profile. Doctors, nurses, paramedical staff, patients and their carers, living with, and working in, rationed and under-served areas of the health services such as neurological disorders, all understand this. However, broad-based support for a more equitable sharing of limited

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resources will be generated if there is a compelling 'case for change' i.e. a rigorous assessment of the strengths and shortcomings of the status quo with a clear unambiguous vision for the future. Recently, a high level group comprising all of the above mentioned stakeholders met over a 12-month period to complete just such an exercise in relation to neurology. The resulting national needs assessment, the Strategic Review of Neurology and Neurophysiology Services in Ireland, has still not been published, despite its recommendations being endorsed by two leading consultant neurologists working in the UK and Netherlands. This has led to a deep sense of disappointment and mistrust among those working in the neurology sector who believe the report continues to be unpublished because of the fear that pressure will build to implement changes that will require a lot of upfront costs. However, this type of short-term thinking has infected Irish health care reform for too long. The case for change is underpinned by hard evidence, and all this evidence points to improved cost control and better quality by managing chronic neurological diseases with proper integration of primary, secondary and tertiary care services. International research clearly shows that outcomes are better when patients have access to the right services in the right places.

## *2. How will the needs of the population grow?*

Planning for sustainability requires an understanding of how and why future health requirements are likely to change. There have been a number of studies recently, which have made projections on the changes in demographics, the ageing population and the increase in formerly rare diseases such as dementia. This research must form the basis of future planning. However, it must also be noted that other drivers for health care such as technology, societal expectations and policy changes can often have as much impact on future cost as demographics.

## *3. What pathways will meet patient's needs?*

The cornerstone of a successful regional neurological strategy is the redesign of clinical pathways to address the issues identified in the case for change and to meet the evolving needs of patients. Clinical pathways are evidence-based guidelines and best practices for achieving desired outcomes and optimal efficiency. Clinicians, managers and patient advocates must work together to develop pathways from end to end. As part of this process they must define the quality standards and protocols for specific pathways, the optimal flows through the system and the process and outcome measures needed to track system quality. An example of a proposed care pathway for epilepsy is included at the end of this chapter.

The Irish Government, and more specifically, the Department of Health and Children (DoHC) has recently produced a policy framework, which specifically addresses the management of certain chronic diseases, Tackling Chronic Disease - A Policy Framework for the Management of Chronic Diseases (DoHC, 2008). It emphasises the current and growing burden of chronic disease. The WHO has attributed 86 per cent of deaths and 77 per cent of the overall disease burden in Europe to this broad group of diseases. Three quarters of people over 75 have at least one chronic condition. In some European countries with older age groups, some 40 per cent of the population are living with a chronic illness. For unclear reasons, the government report conflates mental health and neurological disorders as one under the rubric of 'neuropsychiatric disorders', which is unhelpful since service planning has rarely if ever conflated these two areas. Nevertheless, and unsurprisingly, the patients considered under the term 'neuropsychiatric disorders' comprise the largest group of patients with a chronic disease in the state. The chronic diseases that have been identified in the DoHC policy document largely overlap with those identified by the new office of the director of quality and clinical care as potential pilot programmes.

An important step in identifying needs, developing pathways and evaluating therapies, for chronic disease, is bringing stakeholders together to agree the strategy. Getting such groups together can be challenging, and it is imperative to pilot successful programmes that have proven to embrace change, to have demonstrated collaborative working, effective communication and relationships, as well as having a track record for implementing change. We believe that much of this groundwork has been done for neurological disorders by the national needs assessment group and is outlined in the Strategic Review of Neurology and Neurophysiology services.

Let's make a further assumption at this point, that the needs assessment report, which, by the way has been endorsed by overseas experts, has outlined an integrated, evidence-based, fair and equitable approach to chronic disease management in neurological disorders. At this point implementation, funding and sustainability become central, and this is possibly why the report remains unpublished, which leads to question 4.

## *4. What delivery model should underpin a new national programme for chronic disease management of neurological disorders?*

Implementing the recommendations made in any clinical pathway typically involves making changes in the way care is provided. In London, the NHS framework document Health care for London, adopted a simple maxim: "Decentralise where possible, centralise where necessary". It is important to note that many health systems around the world are trying to make this change. The root of the decentralisation argument movement is to reverse

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the trend in the ecology of health care, which has over the last 20 years seen an increasing reliance on hospital care and a move away from primary care as the gatekeeper of the health of the population. My own personal experience, and that of many of my neurology colleagues in the hospital setting, is that many of our patients just do not interact with their GP or other primary care providers regarding their chronic neurological disease in any way, even to fill prescriptions. Equally GPs have admitted that for certain patients they feel they having nothing to offer such are the perceived complexities of the neurological process. This means that the capacity of hospitals to reach out to the community to identify and treat new cases is severely compromised by large groups of patients attending the hospital ambulatory service for routine follow-up. Thus, waiting lists for neurology are routinely greater than 12 months.

The goal of decentralisation is to try and optimise the patient experience, to provide as much of their health, diagnostic, therapeutic and rehabilitative needs as possible in one local centre. This will then free up ambulatory space at hospital level, thus improving access for those who need more specialised care and opinion.

The goal of centralisation recognises that there is compelling clinical evidence that for certain complex conditions, rapid access to diagnostic and specialised opinion is required. For instance, it is generally agreed that for a patient with first seizures, early referral (within two weeks) to a centre with expertise in epilepsy care is extremely valuable, both diagnostically and therapeutically. Thereafter, however, 70 per cent of patients diagnosed with a tendency to have recurrent seizures will be well controlled on appropriate doses of medication. The vast majority of those could be looked after in a primary care setting so long as clear guidelines for continuing care and intelligent support were provided (see section 'Innovation Working in Practice' by Dr Mary Fitzsimons, which follows, for a discussion on the opportunities afforded by information and communication technology for integrating care).

If we accept that health system reform recognises the need to shift to this delivery model, how do changes in resource allocation support such a model? What incentives can we build into the model that will move us towards such integrated care?

The first necessary change may already be happening with the development of primary care teams, which in theory have the capacity to provide the type of one-stop-shop described above. What is not clear is whether there are basic minimum requirements for these teams: in terms of staff; whether they have the diagnostic equipment and facilities to provide basic level of care, and, most importantly, how the ones that currently exist have 'integrated' with the local specialist centre to try and take over the continuing care of chronic disease. As a neurologist working in a specialised environment in Dublin, where a number of primary care teams have evolved, I have not been made aware of any changes that would allow me to decant patients easily to the community.

An economic model that has a clear idea of what it costs to live with a particular disease or combination of chronic diseases in the community, and that calculates the drugs costs, out-of-pocket expenses and costs of hospital visits (both inpatient and outpatient), needs to be created. This could form the basis of a payment model for a disease. Using a Programme Budgeting Marginal Analysis (PBMA) approach, the marginal analysis would start to make it much more obvious that it could save money by paying primary care teams to do much of the continuing care, reserving the expensive hospital visits for only the refractory or highly complex cases. Thus, the ecology reverses, pushing care into the community and freeing up specialised services for those who really need them.

Between primary care teams and specialised centres, there is huge potential in Ireland for using non-acute, elective hospitals to provide routine neurosurgical and neuromedical care. The development of Irish health care with its political emphasis on local hospitals, means that the infrastructure is already there for such institutions. Again, the PBMA model would make it clear that the programme will save on the margins by using these less expensive clinics for routine care.

In my view, the most important impediment to the development of integrated care is the development of shared goals between the primary care team, elective hospitals and specialised centres for the needs of their patients. These can be laid down in a clear evidence-based way as 'managed care plans' (See Fig 1.3 on epilepsy). The historical structure of GPs as independent providers and some of the perverse incentives of private health care in the specialised centres, are two important reasons why simply developing primary care teams and elective hospitals will not necessarily lead to integration. In the past, initiatives such as the Heartwatch programme have fallen largely because the implementation of the programme was conceived only as a cost to the health service, not as a saving overall by reducing hospital level care. Thus, without a view of the programme budget as a whole - paying out on one margin and saving at the other - it was always destined to be seen as a runaway cost.

It is imperative that whatever economic model is chosen by health reformers, that it creates a balanced incentive between primary care teams and hospitals. For instance, if a proper integrated epilepsy service truly saved bed days, the economic model should be able to translate that into tangible savings that could be fed into the integrated delivery model (i.e. saving 356 bed days is equivalent to closing a bed in a hospital; the economic model must allow health care leaders to close that bed and redeploy the whole time equivalent staff salaries to ambulatory services or into the primary care team itself, whatever priorities the PBMA has decided upon).

### 5. Are the proposed changes affordable and sustainable?

The radical possibilities of health service reform mean that groups of stakeholders, clinicians, managers, patients etc., can now look across the health sectors, from primary care team to specialised centre and see how best they may allocate a fixed resource. More importantly, if they make a decision using best evidence to manage some parts of the condition in more community (less costly) environments; if they manage to deal with patients admitted to specialised centres in more efficient ways (saving bed days); if they, can negotiate nationally on drug costs, managing to move to generic prescribing where appropriate, then they should be also able to realise these savings. Indeed, they should then be allowed to ply those savings back into the service in areas of need, whether that be due to a realigning of standards of care if new international standards are produced, the introduction of a new technology or the perception of a need within the society.

Crucial to this model is information. At the level of the specialised centre and possibly even the elective centre, this costing is available. However, we urgently need to get information from primary care. At present, there are sources of data (census, quarterly household surveys, drug reimbursement schemes, long-term illness schemes) in pilot projects with groups of GPs who are coding in computerised practices. Unless these are undertaken nationally the above model is doomed.

**Fig 1.3**  
**Possible Managed Care plan for epilepsy**

Prevention	Managed Primary Care (PC)	Secondary Hospital Care (SC)	Tertiary Hospital Care regional (RC) centre	National Specialist Centre
<p>Antenatal care</p> <p>Alcohol abuse</p> <p>Stroke Prevention</p> <ul style="list-style-type: none"> <li>- HTN</li> <li>- Cholesterol</li> <li>- Afb</li> <li>- Smoking</li> </ul> <p>Brain Trauma</p> <ul style="list-style-type: none"> <li>- Speeding</li> <li>- Alcohol</li> </ul>	<p>General Epilepsy Care</p> <ul style="list-style-type: none"> <li>- Diagnosis</li> <li>- Classification</li> <li>- Treatment and first aid</li> <li>- Prognosis</li> <li>- Life style triggers</li> <li>- SUDEP</li> </ul> <p>AEDs</p> <ul style="list-style-type: none"> <li>- Choice</li> <li>- Side Effects</li> <li>- Interactions</li> <li>- Long Term Illness card</li> </ul> <p>Women's Issues</p> <ul style="list-style-type: none"> <li>- Contraception</li> <li>- Pregnancy</li> <li>- Breastfeeding</li> </ul> <p>Social Issues</p> <ul style="list-style-type: none"> <li>- Driving</li> <li>- Employment</li> <li>- Safety</li> </ul> <p>Psychology</p> <ul style="list-style-type: none"> <li>- Cognitive effects</li> <li>- Mood effects</li> </ul>	<p>General Epilepsy Care</p> <ul style="list-style-type: none"> <li>- First Seizure</li> <li>- Acute management of refractory seizures</li> <li>- Status Epilepticus</li> </ul> <p>Diagnostics</p> <ul style="list-style-type: none"> <li>- Brain imaging</li> <li>- EEG (if possible)</li> <li>- Classification</li> <li>- Initiate Treatment</li> </ul> <p>Referral</p> <ul style="list-style-type: none"> <li>- Primary Care</li> </ul> <p>Regional Epilepsy Centre and Rapid Access Clinic</p> <ul style="list-style-type: none"> <li>- Mobile phone</li> <li>- E mail</li> <li>- Video Link</li> <li>- Phone</li> <li>- Community</li> <li>- Epilepsy nurse clinic</li> </ul>	<p>General Epilepsy Care</p> <ul style="list-style-type: none"> <li>- First Seizure</li> <li>- Acute management of refractory seizures</li> <li>- Status Epilepticus</li> </ul> <p>Diagnostics</p> <ul style="list-style-type: none"> <li>- Brain Imaging</li> <li>- EEG</li> <li>- Classification</li> <li>- Initiate Treatment</li> <li>- Treatment review for refractory epilepsy</li> <li>- Prognosis</li> </ul> <p>Access from PC and SC</p> <ul style="list-style-type: none"> <li>- Rapid Access Clinic</li> <li>- Subspecialty Epilepsy Clinic</li> <li>- A&amp;E</li> <li>- Video Consultation</li> <li>- E mail/phone/fax</li> <li>- Self management programme</li> </ul> <p>Counselling</p> <ul style="list-style-type: none"> <li>- Epilepsy Nurse Specialist</li> <li>- Nurse Led Clinic</li> <li>- Brainwave CRO</li> </ul>	<p>Pre Surgical Diagnostics</p> <ul style="list-style-type: none"> <li>- Brain Imaging (3T)</li> <li>- EEG</li> <li>- Video-EEG</li> <li>- Classification</li> <li>- Neuropsychology</li> <li>- Neuropsychiatry</li> </ul> <p>Access from PC, SC and RC</p> <ul style="list-style-type: none"> <li>- Rapid Access Clinic</li> <li>- Subspecialty Epilepsy Clinic</li> <li>- A&amp;E</li> <li>- Video-Consultation</li> <li>- E mail/phone/fax</li> </ul> <p>Counselling</p> <ul style="list-style-type: none"> <li>- Epilepsy Nurse Specialist</li> <li>- Nurse Led clinic</li> <li>- Brainwave CRO</li> </ul>

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## **Innovation working in practice**

Mary Fitzsimons, Principal Physicist, Epilepsy Programme, Beaumont Hospital, Dublin

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### **Introduction**

Funded by the Health Research Board, the epilepsy programme at Beaumont Hospital, Dublin is engaged in a research and development programme entitled Revolutionising Chronic Disease Management with Information and Communication Technology: A socio-technical project applied to epilepsy care in Ireland. The objective of this programme of work is to improve quality, safety and efficiency of health services for the benefit of people with epilepsy.

Epilepsy is a chronic neurological disease affecting up to 37,000 people in Ireland. Diagnosis and optimal management relies on input from a number of health care disciplines (e.g. medical, nursing, psychology, administration) in a variety of health care settings (e.g. community, primary care, local hospital, specialist hospital) together with the active participation of the patient (and/or family/carer). However, current models of health care delivery lack integration between the different health care agencies and can result in uncoordinated patient care, conflicting advice, delays in diagnosis and treatment, and redundancy in the system with unnecessary repetition of information gathering and diagnostic investigation. The lack of shareable patient records contributes to this fragmentation. Patient medical records are still largely paper-based with each health care agency keeping its own exclusive records. This limits the sharing and communication of information required to provide continuity of care across multiple health care providers.

An integrated electronic patient record (EPR), stored centrally can improve this situation so that the same health record can be available via a secure internet connection to all authorised health care providers regardless of geographical location. The benefits are that the same patient information is available to each discipline involved in patient care, multiple users of the record can have simultaneous access to the record, and an electronic record is more readily interrogated than paper records.

To achieve the objectives of this research and development programme, researchers engaged with people with epilepsy and their carers, as well as health care providers who are involved in epilepsy care – epileptologists, epilepsy specialist nurses, epilepsy researchers, administrative personnel, GPs, general practice nurses and community nurses – to determine how shared information can facilitate better continuity of care and add value to health service delivery. These studies provided an analysis of the business of epilepsy care in Ireland and informed the requirements for an epilepsy EPR. In an iterative process of design, development and implementation, these requirements have been translated by software engineers into the epilepsy EPR. This is a unique application as there is no comparable epilepsy EPR in the world. The application has successfully been put into use in a demanding health care setting. Personnel involved in epilepsy care and research at Beaumont Hospital are exploiting this enabling technology with clear benefits for patient care. It is also facilitating more timely sharing and exchange of information with clinicians who refer to the epilepsy service at Beaumont Hospital. The EPR contains functionality to capture and store information required for optimal patient care.

Compared to the traditional paper chart, the EPR is having a positive effect on how epilepsy care is delivered. Clinicians believe it is improving quality and safety and is promoting a service that is more responsive to the needs of the patients. Information is available in a more timely fashion and more clinicians have access to the same information thus promoting a model of shared epilepsy care. To date more than 1000 individuals with epilepsy have a validated electronic record. Users of the EPR include consultant epileptologists, non-consultant hospital doctors, clinical nurse specialists, community epilepsy nurses, researchers and clinical administration staff.

### **Benefits of the epilepsy EPR**

The epilepsy EPR can make finding patient information in a complex medical record much easier. For many people with epilepsy, seizure control can be achieved with appropriate anti-epileptic drug (AED) therapy. To optimise AED therapy, clinicians often need to review a patient's prior AED history e.g. dates started and stopped, reasons for discontinuing, side effects or any allergies experienced. For a patient with a history of epilepsy over many years the paper chart can run into a number of telephone book-sized volumes. Between accessing the chart from the records library and reading through it, finding the required information can take hours. With the EPR, the information can be accessed by authorised clinicians from any computer, and a few mouse clicks leads to the complete AED history. This easy interrogation of the record facilitates more proactive patient care.

The epilepsy EPR also facilitates the epilepsy nurse telephone advice line. A patient at home is experiencing an increase in seizures and phones the epilepsy nurse for advice. The nurse needs to access the patient record to provide the appropriate guidance and also needs to discuss the case with the consultant epileptologist. However, the paper chart is in use by another clinician and not available from the records library. With the EPR, complete patient information can be accessed from the nurse's desktop computer, the consultant epileptologist can simultaneously access the same record and together they can discuss the case by phone. The result is quicker advice to the patient and improved quality and safety.

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The EPR also identifies patients who meet criteria for a clinical research study. The epilepsy programme is involved in a number of clinical research projects e.g. advanced neuro-imaging research and pharmacogenetics. Enrolling patients in research projects requires identification of those who meet certain inclusion criteria e.g. patients are within a particular age range, have a particular epilepsy syndrome, have experienced a specific AED side effect. To do this with the paper chart requires accessing hundreds of records from the library and painstakingly reading through the record. This is an extremely labour intensive and time consuming exercise taking weeks, months or even years depending on the scale of the project. The EPR allows interrogation of data for large populations of patients to identify the records of interest in minutes.

Communicating with the referring clinician can be more effective when using the epilepsy EPR. After their consultation with the patient the clinicians at Beaumont Hospital compose a letter to be sent to the referring clinician and possibly copied to others who are involved in that patient's care. This will contain information about the patient's epilepsy diagnosis, AEDs, investigation results, counselling given to the patient on lifestyle and safety issues, and management plan. In the paper-based system the process of producing this letter involves the following steps – the clinician dictates the letter into a dictaphone, a secretary collects the dictation tape, the tape is stored awaiting transcription, the secretary transcribes dictated letters, the typed letter awaits verification by its author, the letter is verified and signed, returned to the secretary, put in envelope and posted. As the secretary has many other responsibilities (e.g. preparations for subsequent clinics) the process can take more than one month to complete. With the EPR the letter can be produced, verified and signed by the clinician at the time of the clinic. Data stored in the different modules of the EPR is automatically pulled into a letter format, the clinician can include additional comments where required. Without delay the letter can be printed and sent by post or electronically. The result is the referring clinician promptly receives more standardised patient information, thus enabling him or her to provide better support for their patients. There is a reduction in transcription error and the clinic secretary can refocus work on activities that will add more value to patient care. Furthermore, there are cost benefits, as every hour of secretarial work saved in letter production will save approximately €30 (there are about 2000 epilepsy outpatients department letters produced at Beaumont per year).

## Conclusion

While the clinical specialty of interest in our project is epilepsy, the model can be applied to other similarly complex chronic conditions. While implementing an EPR involves some technical challenges, there are also organisational, cultural and political matters to be dealt with (e.g. the challenge of implementing an EPR in an organisation where the paper record is the authoritative medium). This constitutes a socio-technical amalgam, which must be carefully managed to fully realise the benefit of EPR technology.

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## PART II THE OPPORTUNITY

**Conclusion:** Neurological conditions: A challenge for health care; an opportunity for change

Ms Anne Winslow

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“Living with MS is very different for each individual. When I was first diagnosed people had an expectation as to how I should look. “But you don’t look sick.” I had a similar stereotyped expectation. I rarely look sick, I rarely am fully conscious that I have MS. But this does not mean that I am not affected by MS each day. I have got used to the lack of sensation in my hands. I have learned to accept that I am not crossed eyed; it’s just what the sensation feels to me in my eye. I have bruises on my body from my injection sites where I administer myself every 48 hours. You may not think I look sick, I don’t look sick but there are days that the complete exhaustion of MS catches up on me and on these days I rely on my instincts to accept that yes, I am sick. I do have MS no matter how healthy I may seem at first.”

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**Neurological conditions: A challenge for health care; an opportunity for change**  
**Anne Winslow, Chair, Neurological Alliance of Ireland (NAI) and CEO, Multiple Sclerosis Society of Ireland**

What is the future for neurological conditions in Ireland? There is no doubt that this area is replete with challenges. We have a historical underdevelopment of specialised services at every stage of the care pathway. The chapters in this publication outline delays in diagnosis, lack of access to prompt treatment, inappropriate patient journeys and resulting distress for individuals and their families.

However, it is also an area of unique opportunity for the Irish health services. Developing a range of services which can respond flexibly to the complex needs of people with neurological conditions is a significant litmus test for our health system. We can gauge the success of many of the changes that are taking place in how we support people with disabilities, in how we ensure high standards of service provision, and in how we use research to inform service delivery by examining their potential to deliver real improvements in quality of life for people with neurological conditions. Our health system must be able to harness the expertise, as well as the goodwill and commitment of all service providers, both statutory and non-statutory, in a way that recognises and rewards innovation and creativity.

It has been our consistent message throughout this publication that the development of neurological care in Ireland continues to be hampered by the lack of a strategic vision for this area within the health services.

There is a critical need to implement the recommendations of a series of reports on specific areas of neurological care in Ireland to address continuing significant gaps in neurospecialist services and personnel. Coupled with this is the necessity for changes in how services are delivered, to ensure that resources are directed to where they are most needed and people with neurological conditions receive the best quality care possible at the appropriate time. The development and implementation of clinical pathways for neurological conditions represents an opportunity to provide integrated care at each stage of the service journey and to guide healthcare staff in identifying and meeting the needs of these individuals at every point where they come into contact with the health system.

We are aware of the significant resources that continue to be invested in health care in Ireland. We are simply requesting an equitable allocation of these resources such that priority is given to neurological care as a historically underdeveloped area, which faces significant demands now and into the future.

The NAI is the representative organisation for non-statutory organisations working with people with neurological conditions. Since the publication of the Standards of Care documents, the umbrella has worked to highlight the need for services for these individuals and their families. The NAI has played a key role in the development of health policy in relation to neurological conditions in Ireland, most recently in its work on the National Neurorehabilitation Strategy. By strengthening and developing the role of the NAI, there is an opportunity for the health service to work together with these organisations to ensure that the needs of the person with a neurological condition are placed at the centre of service design and delivery.

The health service can no longer delay its response to meeting the needs of people with neurological conditions. There is a critical need to recognise that this area represents the next major challenge for health systems in the developed world, as populations age and new treatments and technologies are developed. The Irish health service has an experienced, expert and willing partnership in the NAI and in the contributors to this publication, as well as the many committed people working with people with neurological conditions in Ireland who continue to play a lead role in bringing innovation and best practice to the design and delivery of healthcare. The solutions are there, the stakeholders are ready, the time for action is now.

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**The Neurological Alliance of Ireland is calling for a strategic focus on neurological care in Ireland which will require:**

- the implementation of the existing recommendations in this area, including the Strategic Review of Neurology and Neurophysiology Services and the National Neurorehabilitation Strategy, to create a network of neurospecialist services and personnel, which can respond to current and future demand;
- the need to change and improve the way in which services are delivered in order to address the range of needs of the person with a neurological condition across all areas where they come into contact with the health services
- a clear commitment to prioritising neurological care in Ireland through target setting and year-on-year development plans based on a recognition of the continuing unmet need in this area and emerging demographic trends;
- the support and strengthening of the role of the Neurological Alliance of Ireland as a partner in the development of policy and improvement of practice in neurological care.

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“I was diagnosed with MS in the summer of 2008. It was a crazy summer as my wife was having our first baby at the same time. We were going between maternity and neurology in the same week. It was a shock but also a relief. I suspected MS, but the other possibility by my reckoning was a brain tumour. I was overjoyed when my neuro looked me dead in the eye and said, “M, you have highly aggressive, highly active multiple sclerosis”. With more than 40 lesions, I was never one to do things by halves. It took a few months and many swings and roundabouts before I finally settled. But now, truth be told, I've never been happier. I 'feel' more now, more alive. I appreciate the things I'd forgotten, the sky above my head and the raindrops that fall. This is my blessing. You get the ticket, you take the ride. I'm making the best of it, positivity and humour, you gotta have 'em.”

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## Biography of contributors

**Dr Peter Boers** has been a consultant neurologist at the Mid-Western Regional Hospital, Limerick, since January 2008. Prior to coming to Limerick, he was a staff specialist (consultant) in the neurology and stroke unit at St George Hospital, Sydney, for five years.

**Dr Áine Carroll** is a consultant in rehabilitation medicine at the National Rehabilitation Hospital in Dublin, St Vincent's University Hospital and the Royal Hospital, Donnybrook. Her particular area of interest is acquired brain injury.

**Dr Tracey Cooper** was appointed CEO of the Health Information and Quality Authority in August 2006. During her career Tracey has worked in and advised on a variety of different health systems, served on a number of national task forces, worked closely with health improvement bodies in the UK and with the health and social care system in Northern Ireland. She graduated from Southampton University Medical School in 1990, and subsequently held a number of posts in General Surgery and Accident & Emergency in England and Scotland. She was Locum Consultant in A&E in Chesterfield & North Derbyshire Royal Hospital before leaving clinical practice, becoming more involved in national health reform and taking up a series of senior management posts in the NHS, including Director of Clinical Services for East Midlands Ambulance Service NHS Trust. She joined the NHS Clinical Governance Support Team in 2001 and became Deputy Head and Director of Operations in January 2004.

**Prof David Cotter** works in the Neuropsychiatry Department of Beaumont Hospital. He trained in neuropsychiatry in the Maudsley Hospital in London and in the National Hospital for Neurology and Neurosurgery, Queen Square. He has been funded by research fellowships from the Wellcome Trust and the Medical Research Charities Group (MRCG). His research interests focus particularly on depression and epilepsy.

**Ms Denise Cunningham** is a clinical nurse specialist in epilepsy services working for Brainwave The Irish Epilepsy Association and Adelaide and Meath Hospital Dublin, incorporating the National Children's Hospital (AMNCH). Her qualifications include a Diploma of Higher Education in Nursing Studies from the University of Greenwich, London, a BSc in Nursing Studies from Trinity College Dublin (TCD), ICU course and a Diploma in Management. She has completed her Postgraduate Diploma in Epilepsy from the University of Birmingham, and is currently doing an MSc in Epilepsy. Ms Cunningham's nursing experience ranges from general medical, liver transplants, eyes and intensive care nursing. She has worked as an epilepsy nurse specialist since 2004.

**Dr Mark Delargy** has been a consultant in rehabilitation medicine at the National Rehabilitation Hospital, Beaumont and Mater Hospitals in Dublin since 1994. He has a special interest in neurobehavioural rehabilitation and locked-in syndrome.

**Dr Colin Doherty** is a consultant neurologist at St James's Hospital in Dublin. He was trained in University College Dublin (UCD) and in various Dublin hospitals before moving to Boston in 1998 for subspecialty training in neurology. He completed a residency and two fellowships at Harvard Medical School and returned to Ireland in 2003 to work in the epilepsy department in Beaumont Hospital as a senior lecturer and clinical researcher. Since his appointment to St James's in 2005, Dr Doherty has developed a keen interest in the principles of health care delivery and reform. His epilepsy service received innovation funding from the Health Service Executive / Department of Health and Children in 2008. He is a member of the expert group on resource allocation appointed by the Minister for Health and Children, which is due to report in April 2010.

**Ms Mary Fitzsimons** is Principal Physicist in the Clinical Neuroscience division at Beaumont Hospital, Dublin. Her research interests include magnetic resonance imaging- (MRI-) based brain morphometry and the application of information and communication technology (ICT) to enhance patient care.

**Ms Geraldine Foley** is a clinical specialist occupational therapist in neurology at Beaumont Hospital. She obtained a BSc OT honours degree from TCD in 1997 and completed a Master's in occupational therapy with TCD in 2005.

**Dr Joe Harbison**, Consultant Stroke Physician, St James's Hospital is also a senior lecturer in Medical Gerontology at TCD, and secretary of the Irish Heart Foundation (IHF) stroke council. The Council on Stroke of the IHF was set up in 1997 by way of a concerted action between the IHF and interested health and social care professionals in stroke, as well as the national advocacy organisation for stroke, the Volunteer Stroke Scheme. Dr Desmond O'Neill, a consultant geriatrician at the AMNCH was invited by the IHF to chair the stroke council group, and rapidly formed a modus operandi to ensure national representation of all interested parties was developed. This was by way of stipulating that each national organisation could send up to three delegates to the council, so all were representative, rather than attending as individuals in their own right. At an advocacy level, the council produced the first Irish strategic plan for stroke prevention and care, *Towards Excellence in Stroke Care* [2001], which espoused four main priority actions: a stroke prevention programme, development of stroke units in general hospitals, development of community rehabilitation and support, and the development of a national stroke register. Arising out of this work, the impetus for an Irish National Audit of Stroke Care was developed. The Council on Stroke warmly welcomes the embracing of this concept by the IHF and Department of Health and Children.

**Prof Orla Hardiman**, Clinical Professor (Neurology) at TCD, is a consultant neurologist at the National Neuroscience Centre, Beaumont Hospital Dublin, where she directs the National ALS service, She is also a Health Research Board physician scientist. Her primary research interests include the epidemiology and pathogenesis of motor neurone disease, with particular reference to the identification of genetic susceptibility factors. She is a vocal advocate for quality public health services, and is a founder of the NAI and the Doctors Alliance. Prof Hardiman is an author of over 120 international peer-reviewed research articles, and a member of a number of national and international boards and advisory panels.

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**The Irish Institute of Clinical Neuroscience (IICN)** was established in 1984, with the objectives of “teaching and education of persons in the knowledge of, promotion and organisation of research into the diagnosis and treatment of neurological and neurosurgical disorders in Ireland”. These remain the core objectives, and are supported by members in centres throughout Ireland and abroad. Almost all clinical neuroscience consultants in Ireland, North and south, are active members of the IICN.

**Ms Angela Kerins** is Chief Executive of Rehab Group, a leading voluntary organisation, delivering high-quality, person-centred services to more than 56,000 people with disabilities, older people and others who are marginalised, every year in over 200 locations in Ireland, England, Scotland, Poland and the Netherlands. Ms Kerins has been Chairperson of the Equality Authority since 2007 and recently completed her term as Chairperson of the National Disability Authority. She is also a member of several boards, including the Health Information and Quality Authority (HIQA). She serves on the board of Post Bank and the National Council of the Irish Business and Employers Confederation. She is the Rehab Group permanent representative to the Economic and Social Council of the United Nations. In 2003, Ms Kerins was awarded an honorary Doctorate of Laws (LLD) by UCD in recognition of her work in the disability sector in Ireland.

**The Medical Research Charities Group (MRCG)** is an umbrella group of medical, research and patient support charities, which originally formed to represent the joint interests of charities specialising in restoring health through medical research, diagnosis and treatment and, where possible, the prevention of disease. A core belief of the group is that today's health research is tomorrow's health care.

**Ms Imelda Noone** is Advanced Nurse Practitioner in Stroke Care in St Vincent's University Hospital Dublin, for the past three years, and previously worked for four years as a clinical nurse specialist in stroke care. Ms Noone's previous posts in nursing include staff nurse, clinical nurse manager, assistant director of nursing and director of nursing, prior to going back to clinical practice. She holds an MSc in Health Service Management and Advanced Practice and is a registered nurse prescriber.

**Prof Charles Normand** is the Edward Kennedy Professor for Health Policy and Management at Trinity College Dublin. He is also the Chair of the WHO European Observatory on Health Systems and Policies and a member of the board of St James's Hospital.

**Ms Barbara O'Connell**, MBA Dip COT, is the co-founder and CEO of Acquired Brain Injury Ireland, which provides community and residential rehabilitation programmes to people with ABI. She is an occupational therapist by profession with an MBA. Across her career she has worked directly with clients and staff in adult and adolescent psychiatry, intellectual disability, and for many years as a manager in the National Rehabilitation Hospital. Ms O'Connell is a sister of Peter Bradley, who has an ABI and inspired the foundation of Acquired Brain Injury Ireland.

**Dr Shaun O'Keeffe** is a consultant geriatrician in Galway University Hospitals and chairman of the Irish Society of Physicians in Geriatric Medicine. His major research interests are acute confusion, restless legs syndrome and ethical issues in the older patient.

**Prof Eamon O'Shea** is a personal professor in the Department of Economics and Director of the Irish Centre for Social Gerontology (ICSG) at the National University of Ireland, Galway. He holds an MA from UCD, an MSc from University of York and a PhD from University of Leicester. He has had over 50 papers published in refereed journals over the period 1988 to 2009 inclusive, including publications in top-ranked journals such as the Journal of Health Economics, Social Science and Medicine and European Journal of Public Health. Prof O'Shea has authored or co-authored 15 books and monographs, mainly in the field of ageing and social policy. He has also contributed 25 chapters to various books, mainly on ageing and inequality issues.

**Dr Edward O'Sullivan** is a graduate of University College Cork, and is a full time general practitioner in Cork City. He is Clinical Director, Headache/ Migraine Clinic, Cork University Hospital since 2000, and is the medical advisor to the Migraine Association of Ireland and a member of the International Headache Society's Ethics Committee. Dr O'Sullivan was Chairman of SouthDoc general practice out-of-hours service from 2006-08.

**Dr Niall Pender**, Head of the Department of Psychology and Principal Clinical Neuropsychologist at Beaumont Hospital, Dublin, has worked in neuroscience for almost 20 years, and has a strong research interest in the field. He is currently the president of the Psychological Society of Ireland.

**Anne Winslow** is the Chairperson of NAI and has been working with people with physical disabilities for almost 25 years, initially in social and youth work and then in social/health/personal services policy, development and management both at organisational and national Governmental/statutory levels. Anne has a Masters in Social Science, a postgraduate Diploma in Applied Social Studies and qualifications in health and organisational management. She is currently the Chief Executive of MS Ireland, having previously worked as Director of Services and Deputy Chief Executive with the Irish Wheelchair Association. Anne has a strong track record of initiating programmes/services to improve and support appropriate quality of life and personal outcomes for people living with a disability. She has also represented people with physical disabilities and served on various HSE, Semi-State and Government departmental working groups. Anne is currently the treasurer of the Disability Federation of Ireland.

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### Member Organisations of the Neurological Alliance of Ireland



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(Registered Charity - 10534)

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## RehabGroup

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Volunteer Stroke Scheme  
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