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.

Mary Harney TD
Minister for Health & Children
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)

Acknowledgements

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.
**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.
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.
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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Source: Dr Colin Doherty
“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.”
Chapter 1. Neurological conditions: A challenge for the Irish health system
Prof Orla Hardiman

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 €112 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**

<table>
<thead>
<tr>
<th></th>
<th>2006 CENSUS 4.235m</th>
<th>CSO Population Projection</th>
</tr>
</thead>
<tbody>
<tr>
<td>Persons living with the condition</td>
<td>17% 725,987</td>
<td>2011 4.488 m 762,960 (17%)</td>
</tr>
<tr>
<td>Help with daily activities</td>
<td>0.6% 25,410</td>
<td>2016 4.811 m 26,928 (0.6%)</td>
</tr>
<tr>
<td>Disabled by condition</td>
<td>2% 84,699 (2%)</td>
<td>2021 5.070 m 89,760</td>
</tr>
<tr>
<td>Has condition but able to managelife on daily basis</td>
<td>14.5% 615,879 (14.5%)</td>
<td>699,657</td>
</tr>
<tr>
<td>Number of newly diagnosed each year</td>
<td>1% 43,559 (1%)</td>
<td>50,700</td>
</tr>
<tr>
<td>People caring for person with condition</td>
<td>1.5% 61,709</td>
<td>70,790</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>NEUROLOGICAL CONDITION</th>
<th>NUMBER WITH THE CONDITION IN IRELAND</th>
<th>SOURCE OF INFORMATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s disease and other types of dementia</td>
<td>37,746</td>
<td>O’Shea, E Prof, 2007. Implementing and other types <em>Policy for Dementia Care in Ireland</em>. Ireland: The Alzheimer Society of Ireland; Irish Centre for Social Gerontology, National University of Ireland, Galway.</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>37,000</td>
<td>Linehan, C; Kerr, M P; Walsh, P N; Brady, G; Kelleher, C; Delanty, N; Dawson, F; Glynne, M, 2009. ‘Examining the prevalence of epilepsy and delivery of epilepsy care in Ireland’. <em>Epilepsia</em>, published online.</td>
</tr>
<tr>
<td>Huntington’s disease</td>
<td>400-500</td>
<td>Green A Prof, National Centre for Medical Genetics, Our Lady’s Hospital, Crumlin.</td>
</tr>
<tr>
<td>Migraine</td>
<td>622,000</td>
<td>Steiner, T J et al., 2003. ‘The prevalence and disability burden of adult migraine in England and their relationships to age, years and geographical differences in migraine are not marked’. <em>Cephalalgia</em>, 23 (7): 519-527</td>
</tr>
<tr>
<td>Motor Neurone Disease</td>
<td>250</td>
<td>Irish Motor Neurone Disease Association</td>
</tr>
<tr>
<td>Multiple Sclerosis</td>
<td>8, 000</td>
<td>Tubridy N Dr, Consultant Neurologist, St Vincent’s Hospital, Dublin</td>
</tr>
<tr>
<td>Muscular Dystrophy</td>
<td>556</td>
<td>Muscular Dystrophy Association</td>
</tr>
<tr>
<td>Myasthenia Gravis</td>
<td>350</td>
<td>Myasthenia Gravis Association</td>
</tr>
<tr>
<td>Parkinson’s Disease</td>
<td>6,000-7,000 (1000 over 80; 20-30 per 1000)</td>
<td>(2-3 per 1000 over 60 years of age; 10 per Hauser R [ed], 2006. <em>Parkinson’s disease questions and answers</em>. 5th ed. Florida: Merit International Publishing.</td>
</tr>
<tr>
<td>Syringomyelia</td>
<td>1 in 10,000</td>
<td>Lynch, T Prof. In a communication to Syringomyelia Support Group. Dublin: Mater Hospital</td>
</tr>
</tbody>
</table>

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).
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.

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 of 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.
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 or 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.
The Future of Neurological Conditions in Ireland:
A Challenge for Health Care; An Opportunity for Change

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.

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

<table>
<thead>
<tr>
<th>Acquired Brain Injury</th>
<th>Incident rate /100,000</th>
<th>Prevalence /100,000</th>
<th>Prevalence applied to 2006 Irish Census Data</th>
<th>95% Confidence Interval on Prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Traumatic Brain Injury</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General Population (N=4,239,848)</td>
<td>235 (range 150-300)</td>
<td>1893(US)</td>
<td>80,260</td>
<td>76,679 - 83,842</td>
</tr>
<tr>
<td>Age 15-65 (N=2,907,473)</td>
<td>1.2-2.7</td>
<td>1200(UK)</td>
<td>34,890</td>
<td>32,927 - 36,852</td>
</tr>
<tr>
<td>Cerebrovascular events</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General Population (N=4,239,848)</td>
<td>205</td>
<td>100</td>
<td>4,240</td>
<td>3,409 - 5,070</td>
</tr>
<tr>
<td>Over 55 (N=87,498)</td>
<td>420-620</td>
<td>500</td>
<td>4,375</td>
<td>3,992 - 4,757</td>
</tr>
<tr>
<td>Brain Tumour</td>
<td>16.4</td>
<td>131</td>
<td>5,554</td>
<td>4,604 - 6505</td>
</tr>
</tbody>
</table>

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

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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"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.”
Chapter 2 – The need for a specific response to neurological conditions in the Irish health service

The Neurological Alliance of Ireland

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

**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 non-physically-disabling neurological conditions 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 nÓspidéal [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.
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 Neurological Alliance 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  
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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 it due in terms of service development. Lack of investment in the last 2 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 organization 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.
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 Neuropysiology 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 Neuropysiology 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 practice in neurological care.
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.


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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“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.”
Chapter 3 - The need to develop a network of specialist neurorehabilitation services in Ireland
Dr Áine Carroll, Consultant in Rehabilitation Medicine, National Rehabilitation Hospital

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)

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 (Nyrie 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 healthcare 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.

**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 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.
References


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

Professor Charles Normand

“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.”
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

<table>
<thead>
<tr>
<th>Malignant neoplasm of colon, skin, breast, cervix, testis</th>
<th>Chronic rheumatic heart disease</th>
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</thead>
<tbody>
<tr>
<td>Hodgkin’s disease</td>
<td>Ischaemic heart disease</td>
</tr>
<tr>
<td>Leukaemia</td>
<td>Cerebrovascular disease</td>
</tr>
<tr>
<td>Diabetes mellitus</td>
<td>Respiratory disease</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>Benign prostatic hyperplasia</td>
</tr>
<tr>
<td>Hypertensive disease</td>
<td>Congenital cardiovascular anomalies</td>
</tr>
</tbody>
</table>


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

<table>
<thead>
<tr>
<th>Country</th>
<th>Death Rate</th>
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<tbody>
<tr>
<td>Austria</td>
<td>72.90</td>
</tr>
<tr>
<td>France</td>
<td>42.75</td>
</tr>
<tr>
<td>Greece</td>
<td>72.35</td>
</tr>
<tr>
<td>Portugal</td>
<td>113.64</td>
</tr>
<tr>
<td>UK</td>
<td>87.43</td>
</tr>
</tbody>
</table>

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 [McCance 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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