National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland 2011-2015



An Roinn Sláinte
DEPARTMENT OF HEALTH



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

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Health Service Executive

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Patient Safety First

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Minister's Foreword

Nearly three-quarters of a million people in Ireland today are affected by disabling neurological conditions and/or significant physically disabling conditions. They and their families are challenged by the barriers that are placed on their participation in social and economic life. The care and support needs of this cohort of people are individualised and varied, and present a challenge to the health and personal social services, as well as to the wider public services.

I clearly see and recognise the impact that rehabilitation can play in ensuring that people with neurological presentations can live the life of their choice to the greatest extent possible. Historically, the focus and content of interventions has been on the individual and their limitations. Progressively, this focus and associated model of care has been challenged: today, the focus is on a more holistic social model, where the regime of supports and services is determined by reference to the environment within which the person lives, informed by the diagnosis.

Accordingly, the responses to the individualised need are generally described as a continuum of supports and services, which may be accessed at different stages depending on the need at a particular time. Indeed, at certain stages along this continuum, the primary need and response may not reside within the remit of the health and personal social services, and therein lies the challenge to the wider system and to the need for more collaborative working.

While the focus of the supports and services is on the individual, there is evidence that significant economic benefits can accrue to society from investment in rehabilitation.

I am impressed by the work of the many voluntary agencies that have been to the fore in responding to the needs of particular diagnostic cohorts. The challenge now is to ensure that the content of provision is appropriate to each individual, that the structure of provision facilitates this and that there is an appropriate governance framework.

This very important report, commissioned jointly by the Department of Health and the Health Service Executive (HSE), sets out a clear policy with a recommended service framework that, when implemented, will ensure we meet our obligations to those we serve in the most appropriate, most effective and most efficient way. I look forward to receiving, at a very early stage, a comprehensive implementation plan from the HSE.

I wish to thank all those who have contributed to the development of this National Neuro-Rehabilitation Policy and Strategy and I would ask that all stakeholders commit to its implementation.

Kathleen Lynch, TD
Minister for Disability, Equality, Mental Health and Older People
November 2011

Acknowledgements

Many people were involved in the development of this policy. Thanks are due to the members of the Working Group who worked together in coordinating and guiding the nature and direction of the policy (*see Appendix 1*); also to the advice and expert opinion obtained from four international experts in the field, whose contribution added significantly to the production of this report; and also to the Neurological Alliance of Ireland, which contributed to the process through the provision of an interface with the non-statutory sectoral providers.

Members of the Working Group were responsible for carrying out the evidence review and analysis that informed the writing of this report and they have commented on each draft. Since the report outlines both the policy and strategy for the provision of neuro-rehabilitation services, both the Department of Health and the HSE have shared ownership of the report.

A Steering Group was also established, made up of the relevant management in the HSE and Department of Health (*see Appendix 1*). It met on three occasions and its role was to ensure that the policy was consistent with the current strategic direction established for the health services. The group made important contributions to the proposals for implementation of this policy (*see Chapter 11*).

A large number of people – from service providers to service users and their advocates – contributed in various ways through the consultation process held to inform this policy (*see Appendix 2 for list of submissions*). All the information gathered from this exercise was not only used in the development of this document, but will be used as a baseline in informing further work in this area.

Lastly, credit is due to those involved in authoring and editing the document: Dr. Jane Whelan and Dr. Ina Kelly (Specialist Registrars in Public Health Medicine who were working in the Department of Health) carried out significant work in preparing this policy document; Dr. Fionnuala Cooney (Specialist Registrar working in the Department of Health) conducted a review of the health economics literature; and Ms. Diane Nurse, HSE Social Inclusion, made a significant contribution to the final draft, with input from Dr. Philip Crowley of the Department of Health. Finally, thanks are due to Ms. Eithne Breathnach and Ms. Mags Dorney of the Disability Services in the Department of Health for their support in ensuring that the work of the Group was brought to a conclusion.

James O'Grady
Chairperson
Working Group on Neuro-Rehabilitation Policy and Strategy

Glossary of terms

Multidisciplinary teams: This refers to people from different disciplines working together for the benefit of the service user. Integral to the process are 'communication, collaborative assessments and formulation of integrated goals which take account of environment and participation'.

Neuro-rehabilitation: A problem-solving process in which the person who experiences a neurological impairment or loss of function acquires the knowledge, skills and supports needed for their optimal physical, psychological, social and economic functioning.

Primary care: An approach to care that includes a range of services designed to keep people well, from promotion of health and screening for disease, to assessment, diagnosis, treatment and rehabilitation, as well as personal social services. The services provide first-level contact that is fully accessible by self-referral and have a strong emphasis on working with communities and individuals to improve their health and social well-being.

Self-management: This refers to individuals taking responsibility for their own physical and emotional health and well-being, and includes staying fit and healthy, taking action to prevent illness and accident, using medicine appropriately, seeking prompt treatment for minor physical and emotional ailments, and self-managing long-term conditions appropriately.

Teamwork: Service providers working together to provide a unified service, regardless of their employing body. Supervision or other professional requirements of team members within their own professional disciplines may involve people outside the team, but should support team-working. Administrative structures should also support team-working.

Transdisciplinary working: A transdisciplinary team involves two or more people, including family members, working together to better understand and more effectively and efficiently address the needs of the child and family. Through collaboration, consensus-building, regular and open communication, and expanding roles across discipline boundaries, team members plan and provide integrated services for children and families.

Vocational rehabilitation: This can be defined as enabling individuals with either temporary or permanent disability to access, return to or remain in employment. It involves medical, psychological, social and occupational activities aiming to re-establish among sick or injured people their working capacity and needs for returning to valued social, occupational and economic activity.

Executive Summary

Executive Summary

Chapter 1: Methodology and structure of report

This report is the output of the Working Group jointly established by the Secretary General, Department of Health (then the Department of Health and Children), and the Chief Executive of the Health Service Executive (HSE) to develop a policy and strategy for the rehabilitation of those persons with a neurological presentation or with a significant physical disability.

The Working Group was supported in its work by:

- a number of sub-groups, established to give a detailed consideration and analysis of 5 exemplar conditions that accounted for up to 80% of the cohort being considered (*see Appendix 1*);
- four high-status international experts, who reviewed various position papers;
- the Neurological Alliance of Ireland, which provided much advice and acted as a conduit with those non-statutory agencies involved in neuro-rehabilitation;
- a comprehensive consultation process with stakeholders (*see Appendix 2 for list of submissions*);
- a Steering Group, representative of the Department of Health and the HSE (*see Appendix 1*).

The following pages summarise the main points in each chapter of the report.

PART 1: CURRENT NEURO-REHABILITATION SERVICES

Chapter 2: Key characteristics and considerations of neuro-rehabilitation services

Neurological illness or injury has significant implications for the individual and their family, and impacts on their social, educational, vocational and recreational participation. It is essential that high-quality, cost-effective rehabilitation in all its facets is available and is geared towards empowering the individual and their family in maintaining optimal participation in society.

Thus it is important that the continuum of services and supports required are made available by the health system and by those other State agencies that have both an opportunity and an obligation to provide specific services, consistent with their statutory remit. Current health-provided neuro-rehabilitation services are provided across a range of settings, by different organisations and by many health professionals and carers.

It is well-established and acknowledged that, historically, neuro-rehabilitation services have been underdeveloped and where they exist, have been developed in an ad hoc manner, primarily by the voluntary sector. Where services have been developed by the statutory health system, the focus of provision has been on medical rehabilitation, which, while most important, is not comprehensive. It is also a feature of current provision that many of the services and service structures are condition-specific, with access to some also determined by reference to age within the adult cohort.

Information on the prevalence and numbers requiring and benefiting from neuro-rehabilitation in Ireland is scarce. Similarly, there are many societal changes, changing family structures and patterns, as well as the many advances in medicine and related specialties, that are impacting on people presenting with neurological conditions. This, in turn, has placed increasing responsibility and obligations on the health and wider support services, and highlights the need for evidence-based planning and associated utilisation of resources.

At an individual level, the impact of not receiving appropriate and timely services and supports can include deterioration in function and the associated physical and psychological sequelae. At a system level, it can lead to increased hospital admissions, with consequential delayed discharges and with many of the early advances negated by the absence of downstream services.

Research on the health economics of neuro-rehabilitation, which though small and narrow, indicates that there are substantial benefits to be had from such services and that models of community-based provision surpass conventional hospital-based services in terms of economic efficiency. General research clearly supports early intervention, both in terms of personal outcomes for the individual and also the reduced costs to the system.

Key messages from the consultation exercise

In total, 77 submissions were received and analysed under key themes, which included:

- The absence of and inability to traverse the healthcare system, particularly post-discharge from in-patient services.
- Services should be needs-led, regardless of age and diagnosis.
- The absence of a team approach in the management regime, with many of the professionals not having the competency to meet the assessed need.
- The absence of rehabilitation services in nursing homes.
- The need to involve families and carers as active members of the rehabilitation team.
- Under-utilisation of essential aids, appliances and, in particular, assistive technologies.
- Concerns at the sustainability of current models and structures.

It is clear that in the current economic climate and given changing demographics and enhanced expectations, there is an urgent need for new policy and service frameworks. In the short to medium term, the focus has to be on reconfiguration of services, structures and resources, and the enhancement of the skills and competencies required to meet the changing context.

In summary, any new policy and service frameworks must have clear service objectives and outcomes, with a governance framework that facilitates these in the most efficient way.

It is the changing expectations of those served and their families that dictates the need to review what we do and how it is done, and to ensure that the right services and supports are provided and that they are provided in the right way. In essence, people are demanding services and supports that enable them to live the life of their choice.

Chapter 3: Purpose, scope and vision of Neuro-Rehabilitation Policy and Strategy

Currently, there is no single policy that informs practice. However, there are numerous operational policies self-determined by agencies, professions and service settings that have a focus on sustaining a particular sectoral interest.

The commissioners of the present report indicated that its purpose and scope was to provide a single national policy and strategy to guide, govern and determine service response and structure. Based on the analysis of current practice and the wider context, a policy and strategy framework is being recommended here to express specific policy objectives for people presenting with neurological or other significantly disabling conditions, and for services to support the achievement of these objectives.

The vision proposed is that people presenting with neuro-rehabilitation needs are supported to participate as fully as possible in the social and economic life of their community and have access to a range of quality services and supports so as to enhance their quality of life and well-being.

The vision is underpinned by key principles and values, and has two overarching goals:

- **Goal 1** is to provide a service that is LITI, meaning:
  - **L**ocal – *Rehabilitation where I need it*.
  - **I**ndividualised – *Rehabilitation the way I need it*.
  - **T**imely – *Rehabilitation when I need it*.
  - **I**ntegrated – *Rehabilitation should I need it*.

The underpinning principles of Goal 1 are:
  - person-centred;
  - dignity and respect;
  - service user participation;
  - responsive to need;
  - access to information.

- **Goal 2** is the creation of a flexible, responsive and accountable system that will fully support the realisation of Goal 1, with the following underpinning principles:
  - equity;
  - person-centred;
  - effective;
  - efficient;
  - quality;
  - accountable and transparent;
  - responsive.

Chapter 4: Strategic context for developing a Neuro-Rehabilitation Policy and Strategy

The development of a national policy and strategy should be viewed against a background of the Department of Health's National Health Strategy (2001a), which advocates a whole-system approach to improving health and social gain in Ireland. This approach is mirrored in the HSE's *Transformation Programme 2007-2010*, which identifies the need to develop an integrated health and social care model. It must be noted that the HSE is very reliant on its partnership arrangements with the non-statutory sector to provide a wide range of services and supports in the area of neuro-rehabilitation.

It is essential that those tasked with implementing the new policy and strategy ensure that the roles and functions of the statutory and non-statutory sectors are complementary rather than competitive, thus ensuring that available resources and capacity are mobilised for the optimal rehabilitation provision of all people with needs consistent with their neurological presentations.

There are numerous national and international legislative and policy frameworks that govern disability and rehabilitation provision, including:

- United Nations Convention on the Rights of Persons with a Disability (2008);
- United Nations Convention on the Rights of the Child (1989);
- Equal Status Acts 2000-2004 (2000);
- Disability Act 2005 (2005);
- National Health Strategy (2001);
- National Audit of Stroke Care (2008);
- National Cardiovascular Health Policy 2010-2019 (2010).

PART 2: PLANNING TOWARDS EFFECTIVE NEURO-REHABILITATION SERVICES

Chapter 5: Needs analyses and mapping of neuro-rehabilitation service provision in Ireland

Needs analyses

The inadequacy of current information collection and application of data, together with the even more limited information on prevalence rates, provides a major barrier to quantification of the numbers of people needing access to neuro-rehabilitation in Ireland. In recognition of this, additional measures were taken by the Working Group to strengthen and inform an evidence-based development of this policy. Five of the more common neurological conditions were selected for detailed review and analysis, so as to more fully inform the types of service needs across a continuum of care. The 5 conditions selected were:

- acquired brain injury (other than stroke);
- cerebral palsy;
- multiple sclerosis;
- idiopathic Parkinson's disease;
- spinal cord injury.

The needs assessment process identified:

- The benefits of early, intensive, coordinated rehabilitation.
- Settings for services need to be determined by reference to the complexity of the condition, by the competencies of the providers in such settings and by the phase of the neuro-rehabilitation. In that context:
  - acquired brain injury is deemed to be a high-prevalence condition with variable complexity;
  - cerebral palsy is a moderate prevalence condition, presenting in childhood with variable complexity;
  - idiopathic Parkinson's disease is a moderate condition with variable complexity;
  - multiple sclerosis is moderately prevalent with variable complexity;
  - spinal cord injury is a low-incidence, high-complexity condition.

Mapping of neuro-rehabilitation service provision in Ireland

A national mapping exercise was carried out as part of the work of the Working Group in order to identify the service gaps and deficits. The exercise proved particularly challenging when trying to determine dedicated resources in generic health settings.

Key issues and conclusions from the mapping exercise were:

- Due to lack of validation of data submitted, it was not possible to map out precisely the levels of services being provided.
- There were a very high number of condition-specific service settings, with some settings also confining access to certain adult age cohorts.

- Specialist in-patient services are mostly concentrated at national level.
- Services in the community, although not inconsiderable, are very fragmented and many of them are in specialist settings, with little, if any, coordination.
- It is acknowledged that because of the significant fragmentation, the structure of provision may well be a contributor to the lack of services.
- The current service procurement arrangements in place between the HSE and voluntary service providers are also a contributor to the fragmentation and inequity of provision since the various service arrangements are based on organisations' mission statements and competencies, rather than on the service specification of the HSE.

Chapter 6: Pointing the way to a national model of service delivery

Arising from the needs analyses, the service mapping project and general consultation, a number of key issues have been identified that need to be considered in putting forward any service improvement proposal:

- accessing services;
- service delivery structure;
- promoting health and social gain;
- factors underpinning planning and service delivery;
- measuring service effectiveness, efficiency and value for money.

Review by international experts

The Working Group submitted a number of draft position papers to the four international experts advising on the neuro-rehabilitation policy and their comments and recommendations were most helpful in informing the final output from the Group. Their recommendations included:

- The need to reconfigure around a more generic neuro-rehabilitation structure.
- The need to have a formal connection between the different stages along the continuum of supports.
- In promoting an integrated model, a hub and spoke structure was strongly recommended, as long as resources are appropriately aligned.
- Neuro-rehabilitation services need to be person-centred since the need cannot be predicted by reference to the underlying diagnosis.
- Community-based services must have access to and be supported by a regional team, which, in turn, should be led by a clinician who has the vision and the confidence of both the regional and community teams.

PART 3: A FRAMEWORK FOR FUTURE SERVICE PROVISION

Chapter 7: Proposed framework for neuro-rehabilitation service provision

Neuro-rehabilitation is a continuum of services and supports that will require responses to individual need at local, regional and national level, with the following key characteristics:

- Access to services along the continuum must be determined and informed by clear referral and practice protocols that are developed nationally and that have to be implemented consistently across the system.
- The structure and protocols must maximise the natural supports that are available both in the home and in the community.
- Service flexibility and continuity must ensure that individuals may enter the services at a stage in the continuum that is most appropriate to meeting their need at the particular time.
- An appropriate management and governance arrangement must be put in place.
- While the focus of the work of the Working Group was on the health components of the policy and strategy, it is critical from the individual perspective that those State agencies with an obligation to provide non-health supports commit to supporting the individual to overcome those barriers to participation by virtue of their disability.

Chapter 8: Key approaches underpinning the proposed neuro-rehabilitation service framework

A key prerequisite to having an appropriate neuro-rehabilitation service is the existence of a high-quality neurological service that will ensure timely and accurate diagnosis and timely referrals to neuro-rehabilitation.

The building blocks for a service framework include the following elements working together:

- incorporation of health prevention and promotion strategies;
- the development of managed networks that will ensure and promote excellence and consistency, and that will support integration;
- a community-based rehabilitation approach;
- clear linkages and pathways across service levels and settings;
- increased use of research and technology;
- establishment of an agreed quality framework;
- intersectoral commitment.

Chapter 9: Range of service provision in the proposed neuro-rehabilitation service framework

The future model will offer a clear continuum of services and supports that will be provided at local, regional and national level, depending on complexity and volume. These services and supports will be accessed at:

- Primary Care Teams, where services will be general in content with low to moderate intensity therapy.
- Geographic-based Community Neuro-Rehabilitation Teams, where specialised services will be provided to those with moderate to high-intensity therapy needs.
- Regional neuro-rehabilitation services with access through acute hospitals and directly from the national centre(s) or from the Community-based Teams, and providing high-intensity in-patient therapy and out-patient services.
- National neuro-rehabilitation services, catering for low-incidence, highly complex cases that are beyond the reach and competency of the regional services.

Neuro-rehabilitation service for children

The approach to services for children is quite distinct from that of adults. Services for children focus on:

- children with delayed conditions (congenital) who require input to achieve developmental milestones and goals;
- children with progressive conditions who require input to minimise loss of function;
- children with traumatic injury who require input to maximise gain and restoration of function.

Clear protocols need to be developed to enable the transitioning from paediatric services to adult services. The Working Group reflected on the unique needs of children and the specific obligations to them as provided for in legislation. It was concluded that the best interests of children with neurological presentations and associated needs are best served by including such children within a children's framework. Accordingly, the Working Group has recommended that this cohort needs to be included in the work being done through the reconfiguration of paediatric services.

Chapter 10: Assuring quality

The need to establish a quality framework has been a recurring theme. This framework will need to incorporate and ensure:

- clinical effectiveness;
- staff learning, training and development;
- staffing levels and integrated workforce planning;
- accreditation of all services and service settings.

Chapter 11: Ensuring implementation

Implementation of the National Neuro-Rehabilitation Policy and Strategy will only be achieved when there is proactive leadership at corporate and clinical level. This, in turn, will facilitate the mobilisation of existing resources consistent with the identified framework.

Some initial work has been undertaken on an implementation plan with the HSE and specific targeted actions are included in the HSE's *National Service Plan 2011*.

A final implementation plan would need to set out clear actions, with timelines and performance indicators, starting with an early focus on reconfiguration of existing structures and services. This plan should specifically include:

- a comprehensive mapping exercise of all existing services;
- network development;
- practice and referral protocols both between service levels and settings and between those other services that fall within the remit of other State agencies, but which contribute to the rehabilitation continuum;
- engagement with organisations in the voluntary sector around the new reconfiguration and the implications for them and their staff.

The report ends with the **References** used to inform the National Policy and Strategy, followed by three **Appendices**, detailing the members of the Neuro-Rehabilitation Steering Group, Working Group and Sub-Groups; a list of the submissions received in the public consultation process; and a review of current neuro-rehabilitation service providers.

1. Methodology and structure of report

1. Methodology and structure of report

Methodology

A Working Group representing policy-makers, managers, service providers and service users was established to develop this National Policy and Strategy for the Provision of Neuro-Rehabilitation Services 2011-2015, at the joint request of Mr. Michael Scanlon, Secretary General of the Department of Health (then the Department of Health and Children), and Professor Brendan Drumm, Chief Executive Officer of the Health Service Executive (HSE). The Working Group had strong representation both from service users, whose involvement is critical in the development of policy and strategy, and from front-line services. A Steering Group also met occasionally to ensure that senior HSE and Department of Health management could support the development of the policy. Sub-groups of the Working Group were set up to analyse the service needs of 5 key neurological conditions through a review of international evidence, with the purpose of drawing up an analysis of the need for neuro-rehabilitation services generally and of developing a framework for future services. Membership of these various working groups is provided in Appendix 1.

Working Group's Terms of Reference

The terms of reference of the Working Group were:

1. To consider the rehabilitation needs at acute and community levels of people at all stages of the lifecycle with:
    - static and progressive neurological conditions
    - traumatic and non-traumatic brain injury
    - other physically disabling conditions

    who may benefit from medical, psychological and/or social rehabilitation service provision.

2. The objectives of this process are the development of:
    - an appropriate policy framework;
    - a strategy for service provision;
    - a preferred model of care.

3. A report, to be prepared for submission to the Secretary General of the Department of Health and the CEO of the HSE.

Needs analyses

Five conditions were selected for detailed needs analyses in order to identify the types of services needed across the spectrum of need. These were acquired brain injury (other than stroke); cerebral palsy; multiple sclerosis; idiopathic Parkinson's disease; and spinal cord injury. The epidemiology of these conditions

and the evidence supporting neuro-rehabilitation services for each was examined. These needs analyses informed the development of the policy, taking into account that this policy is based on an understanding of *neuro-rehabilitation needs as arising from functional and capacity needs that occur from different disease processes, but that these needs are not disease-specific*.

Framework for future services

One sub-group of the Working Group examined the international literature on the frameworks used in the provision of neuro-rehabilitation services, identifying the elements of service needed and how these could best be provided in an Irish context (*see Appendix 1, Sub-group on Model of Care*).

Public consultation

Submissions were sought from the public, user groups and service providers in order to ensure that the policy would be informed by as wide a range of views as possible. These submissions were analysed, using content analysis techniques, in order to ensure that common and dissimilar themes were elicited. A full list of the submissions received is provided in Appendix 2.

Existing services

Detailed quantitative data on the neuro-rehabilitation services currently available in Ireland were examined. A SWOT analysis was also carried out to identify service providers' views on the strengths, weaknesses, opportunities and threats for future service development.

Existing policy and strategy

Since neuro-rehabilitation policy and strategy overlap with other Government policies and strategies, cognisance was given to ensuring consistency with these.

International review

A draft of the report was reviewed by four international experts to ensure that it was consistent with best practice trends in neuro-rehabilitation policy. The experts involved were:

- **Professor Alan Thompson**, Director, Institute of Neurology, University College London; Deputy Director, Comprehensive Biomedical Research Centre, University College London and University College London Hospital; and Garfield Weston Professor of Neurology and Neuro-Rehabilitation, Institute of Neurology, University College London.
- **Dr. Jurg Kesselring**, Head of the Department of Neurology, Rehabilitation Centre, Valens, Switzerland.

- **Professor Lyndsay McLellan**, National Consultant Advisor for the Priory Group's Neurological Rehabilitation Division; Medical Director at Unsted Park Hospital; and previously Europe Professor of Rehabilitation, University of Southampton.
- **Jacqui Lunday**, Director of the Allied Health Professionals, NHS Scotland.

Coordination by Neurological Alliance of Ireland

The Neurological Alliance of Ireland (NAI) facilitated a parallel process, coordinating the input of the non-statutory sector providers at all stages of the policy development.

Structure of report

Part 1 presents an overview of current rehabilitation services, together with an overall perspective on the factors influencing and driving them. Initial proposals are then considered to reconfigure rehabilitation services within a context of reform of the health system and a genuine shift towards a more social model of disability.

- *Chapter 2* describes the current status of rehabilitation services in Ireland, with analysis of present delivery of services, numbers accessing these services, the challenges involved, the impact better services would have and the economic case for improving services.
- *Chapter 3* describes the purpose, scope and vision of this neuro-rehabilitation policy and strategy, together with the values and principles underpinning it.
- *Chapter 4* examines the strategic context in which the policy is being developed, both internationally and nationally, and describes the roles and functions of the two key statutory bodies involved – the Department of Health and the Health Service Executive (HSE).

Part 2 moves from this broad approach into a more detailed analysis of current ways in which services are provided and the identified strengths, weaknesses and gaps around this. The deficit in data around neuro-rehabilitation has been acknowledged. Much work has been undertaken during the development of this report to form a more complete picture of service users' needs, coupled with current service provision and identified gaps in delivery of neuro-rehabilitation. The information derived from these exercises and the conclusions drawn form the basis for this part of the report. While the data are not sufficiently comprehensive to present a full picture of needs and services across the country, they provide a firm foundation on which to analyse the strengths and deficits of the present system of neuro-rehabilitation services and to make informed proposals on a future direction for service provision.

- *Chapter 5* describes the findings of the needs analyses exercise and links these findings with the results of the service mapping process.
- *Chapter 6* analyses these results and, combined with learning from the extensive consultation process, leads to the identification of priorities for future service delivery.

This lays the foundation for **Part 3** of the report, which outlines a clear framework for neuro-rehabilitation services to be planned and provided on a strong evidence base and in a coherent integrated manner.

- *Chapter 7* describes the proposed new framework for delivery of neuro-rehabilitation services.
- *Chapter 8* analyses key approaches to this framework.
- *Chapter 9* describes the range of care proposed for neuro-rehabilitation – from primary and community-based care, to hospital services, to national or tertiary care, including children's services.
- *Chapter 10* discusses ways of assuring quality of services.
- *Chapter 11* proposes ways of ensuring implementation of the policy.

Three appendices end the report:

- *Appendix 1* lists the memberships of the Steering Group, Working Group and Sub-groups on the National Policy and Strategy for the Provision of Neuro-Rehabilitation Services 2011-2015.
- *Appendix 2* lists the submissions received in the public consultation process.
- *Appendix 3* describes the current neuro-rehabilitation service providers.

PART 1:

CURRENT NEURO-REHABILITATION SERVICES

2. Key characteristics and considerations of neuro-rehabilitation services

Sustaining neurological injury or illness, or developing a progressive or chronic recurring neurological condition, is a significant event for the individual concerned, as well as for his or her family. This holds implications for all aspects of daily life, including social, educational, vocational and recreational participation. The impacts of such an event are also felt by families and society as a whole, while many of the effects of a neurological illness or disability are also exacerbated by the disabling effects of the physical environment, transport, attitudes and inadequate personal and social services. Many service users who sustain neurological illness or injury are in the prime of life, supporting families and contributing to all aspects of social, economic and personal life. For this potential to continue to be realised, it is essential that quality, cost-effective rehabilitation is geared towards empowering the person and his or her family and community to regain and maintain optimal participation in society.

The needs of such a person and the elements of care and support required to meet these needs are numerous and in some cases very complex. They include medical, nursing and therapy services, as well the various supports to enable access to education, employment, transport, accommodation, recreation and community life. However, the primary focus of this policy is on the health-related services and supports, while referencing those support structures that are required but which come within the remit of other agencies.

People accessing neuro-rehabilitation services range in age from children with neurological conditions from birth, through young and more mature adults with acquired injuries or degenerative conditions, through to elderly people with stroke or other conditions. For most, curative treatments are not available; however, excellent quality of life and good participation in peer group activities can be regained through neuro-rehabilitation. Successful rehabilitation means that the individual is supported to attain optimal function and to live as full and independent a life as possible. Thus, service user satisfaction and improved quality of life are important outcome measures for future services.

While there is no single, universally accepted definition of neuro-rehabilitation, or a theoretical model describing this, the concept of neuro-rehabilitation for the purposes of this report uses the World Health Organization's definition, as follows: ***A problem-solving process in which the person who experiences a neurological impairment or loss of function acquires the knowledge, skills and supports needed for their optimal physical, psychological, social and economic functioning***.

This WHO definition acknowledges the centrality of the service user in the rehabilitation process. This approach towards an enabling model of neuro-

rehabilitation should facilitate improving the partnership between service users, their carers and service providers, so that appropriate intervention will be accessible as required and that resources, both human, financial and infrastructural, can be best utilised, with the aim of enhanced outcomes being assured for individuals, as well as for the delivery system itself.

Such a *person-centred approach* also promotes opportunities for 'self-management', where the individual is directly involved in planning and decision-making around their needs and takes responsibility for maintaining optimal health, functioning and participation. In the case of children, a *family-centred approach* must be embraced, which emphasizes the importance of the child within his or her family unit and the need to support parents and siblings, as well as the child him or herself.

A review by Gutenbrunner *et al* (2006) highlights that patient education – frequently overlooked since it may produce negligible clinical gains – results in significant savings on follow-on, long-term costs. If future medical costs are to be contained, especially in the context of an ageing population, then patient education should be central to rehabilitation care. On a similar note, the 'Getting the Balance Right' (GTBR) project run by MS Ireland has demonstrated clearly the benefits of physical exercise for many categories of people with MS; the results have been not only statistically significant, but also clinically significant (Coote, 2009).

The WHO definition also takes account of the longer term needs of people requiring neuro-rehabilitation. Implicit in this is the inclusion of services aimed at restoring optimal function, as well as those services targeted towards minimising the impacts of illness or injury, preventing deterioration of function and maintaining well-being. This is particularly relevant for service users diagnosed with progressive neurological conditions.

The present policy and strategy is focused on the specific needs of those with neurological illness or injury. The *Vision for Change* policy, published by the Department of Health and Children in 2006, deals with the rehabilitation and recovery of those with mental illness. The HSE has been carrying out a review of rheumatological services that will encompass rehabilitation in that area. The recently published *Changing Cardiovascular Health: National Cardiovascular Health Policy 2010-2019* covers the rehabilitation of those with heart disease and stroke (Department of Health and Children, 2010). The policy on the rehabilitation needs of those with stroke is being developed in coordination with the cardiovascular policy since stroke represents the greatest area of need for neuro-rehabilitation care in the Irish health services.

Neuro-rehabilitation is required for people who typically:

- experience a neurological injury or illness, and will require acute neuro-rehabilitation and/or need post-acute, community and sustaining neuro-rehabilitation services;

- develop a progressive or chronic, recurring neurological condition and may need bursts of intensive neuro-rehabilitation, as well as post-acute, community and sustaining neuro-rehabilitation services.

The causes of disability requiring neuro-rehabilitation are myriad and may be congenital or acquired. Conditions that contribute to the needs for neuro-rehabilitation include:

- neurological conditions (including stroke, acquired brain injury (ABI), spinal cord injury (SCI), multiple sclerosis (MS), Parkinson's disease, cerebral palsy (CP), motor neurone disease (MND), peripheral neuropathy, spinal tumours, encephalitis and meningitis);
- musculo-skeletal conditions (including orthopaedic, limb absence, pain, arthritis and muscular dystrophy);
- multiple trauma;
- a range of other debilitating illnesses and conditions.

Sequelae of these conditions range in nature and level of severity, and may include impairments in mobility, cognition, speech, swallowing, perception and respiratory function. The spectrum of needs ranges from service users with high-level needs for ventilation, assisted feeding and overall 24-hour care, to those who have limited mobility and are able to manage their conditions independently with minimal care and support. In many neurological conditions, challenging behaviour may overlay physical and sensory symptoms. Some will have cognitive behavioural difficulties, where their personality may change, where their ability to organise and make decisions is impaired, and where their ability to socially interact is weakened.

The many diverse needs of people diagnosed with neurological or neurosurgical conditions result in requirements for a wide range of clinical services, both in terms of primary conditions as well as in respect of sequelae of these, together with other co-morbidities. Thus, many additional services play a critical part in responding to need (e.g. dietetics, palliative care, psychiatry, orthopaedics, pain management, urologists, general practitioners and social work), particularly when delivered through trans- or multidisciplinary working in integrated service provision. Other care and support services are also required to facilitate maximum autonomy: these range from personal assistance, nursing care and home support services provided through the HSE, to housing, vocational, educational, transport and other services provided by other sectors. It is important to stress that there is no pre-determined priority or hierarchy of response. This will be determined by the needs of the individual at a particular time as prioritised by their needs assessment.

Current service delivery

Neuro-rehabilitation is part of the management of most neurological and neurosurgical conditions, particularly those that cause, or have the potential to cause, ongoing disability. Neuro-rehabilitation services are presently delivered

across a range of settings, from acute hospitals and specialised neuro-rehabilitation centres, to primary and community settings, including home. The integral role played by the community and non-statutory sector in service delivery is acknowledged from the outset of this report. A key feature of current service delivery structure is the condition-specific structure existing within statutory and non-statutory provision.

Service user neuro-rehabilitation needs range from intensive, acute treatment at tertiary level through to long-term neuro-rehabilitation at community level. Carers, in their many manifestations, play a central role in responding to the needs of this cohort. These carers need to be included when designing and planning those elements of the support continuum that are delivered in the home and community. The development of Primary Care Teams is intended to significantly enhance current capability within the primary and community services by facilitating access to therapeutic interventions, which will be complemented by provision within the specialist community services, regional services and those delivered at national level.

Responsibility for responding to the health and personal social service needs of people who require, or who could benefit from, rehabilitation rests with the Health Service Executive (HSE). The HSE, in turn, has developed contractual arrangements with agencies, the vast majority of which are community, not-for-profit organisations, set up to address an unmet need. These service arrangements are underpinned by a service agreement with the HSE, which is intended to describe in some detail the service provided and by whom. The Department of Health, in collaboration with key stakeholders, is currently carrying out a Value for Money and Policy Review of HSE-delivered disability services. The outcome of this review may well have implications for current service arrangements, structures and content of provision as they apply to the HSE and to those agencies who are either contracted by or grant-aided by the HSE to provide services.

Part 2 of the Disability Act 2005 sets out the framework for the assessment of need of persons with a disability by virtue of their disability. To date, it has been implemented for children aged 0-5 years (with the assessment function remaining directly with the HSE and the consequential service response being provided either by the HSE or a contracted agency) and has yet to be implemented for adults. The Act does, however, provide a framework that could be appropriately applied in respect of the assessment of need of those who require, or who could benefit from, a neuro-rehabilitation service.

For children with neurological difficulties, the Department of Education plays a key role in terms of special school or class facilities and/or a range of supports, such as special needs assistants, resource hours and home tuition. The legal framework governing the provision of education and the health-related supports for such children is set out in the Education of Persons with Special Educational Needs Act 2004. While this Act has yet to be commenced, it sets out clearly the framework for assessment of need.

It is acknowledged that, historically, services in the area of neuro-rehabilitation have been underdeveloped in Ireland and where they exist, they have been developed in an ad hoc manner, leading to fragmented services around the country. It is generally accepted that services are in place following acute illness or injury, but ongoing support has not been as easily accessible. In the past where the health system failed or was unable to respond holistically, the voluntary sector stepped in, which has resulted in the emergence of many condition-specific support groups. A significant component of their support was by way of advice and advocacy. In recent years, some of these agencies have developed formalised arrangements with the health sector to provide elements of support and care. This has contributed to fragmentation within the delivery system, where service users have not always been able to access timely services along a seamless continuum of provision. Impacts on the system arising from disjointed neuro-rehabilitation service delivery range from poorer health and quality of life outcomes for service users and their families/carers, to increased pressures on the overall health system caused by delayed discharges of patients to appropriate settings, repeated re-admissions to hospitals and associated wastage of resources. For example, the prevalence of acquired brain injury (ABI) in the population may be in excess of 250 per 100,000 persons. Services are available at the acute care stage, but recent advances in acute medicine leave more people surviving the initial injury. Users complain that services are insufficient and not focused on neuro-rehabilitation, particularly community-based specialist services. This, in turn, has negated much of the progress made by the person while under the care of the acute/national centre.

Physical and Rehabilitation Medicine (PRM) is an internationally recognised medical specialty that is under-represented in Ireland. Table 1 has been generated from Appendix III of the *White Book on Physical and Rehabilitation Medicine in Europe* by Gutenbrunner *et al* (2006). The figures for Ireland reflect the most recent appointments and the latest Census figures (2006), while all other figures are dated 2007. However, reasonable comparisons can be made, which show that Ireland has the lowest ratio of PRM specialists per 100,000 population of the countries listed.

Table 1: Physical and Rehabilitation Medicine (PRM) in Europe (2006-2007)

Country	PRM Specialists	Population	Ratio of PRM Specialists per 100,000 population
Ireland	6	4,239,848 (2006 Census)	0.141
United Kingdom	129	58,000,000	0.222
Germany	1,571	80,000,000	1.964
Sweden	160	8,500,000	1.882
Iceland	10	270,000	3.707
Slovenia	68	2,000,000	3.400
Malta	1	400,000	0.250
Poland	900	39,000,000	2.307
France	1,760	61,300,000	2.871

Source: Gutenbrunner *et al* (2006)

The personal experience of some members of the Working Group (as clients of rehabilitation services abroad) confirms this scarcity of intensive rehabilitation in Ireland. Ireland remains far behind the rest of Europe in the provision and recognition of intensive rehabilitation. Access to Physical and Rehabilitation Medicine must be a cornerstone of any policy and strategy framework.

Numbers accessing neuro-rehabilitation services

Accurate information is very limited in relation to the number of people requiring neuro-rehabilitation services in Ireland. Nonetheless, Part 2 of this report offers some further detail on the number of people expected to require neuro-rehabilitation services. Census 2006 indicates that almost 394,000 people (9.3% of the population) reported as having an enduring health condition or disability. Many of these will have cardiovascular or musculo-skeletal presentations. Almost 269,000 of this cohort (62%) reported having more than one disability. Further in-depth findings of the Census indicate that the prevalence of disability was higher in urban than in rural areas (9.3% compared with 8.6%), higher among females than males (9.6% compared with 9%) and also highly correlated with age (58% of people with a disability were aged 50 years or over). People with disability showed a lower rate of participation in the labour force (46.4% of males aged 15-64 with disability, compared to 81% of all males in the same age group). One in 5 disabled people live alone, with the proportion of those aged over 65 living alone increasing to 1 in 3. Clearly, this information has implications for the way in which services are designed and delivered.

The 2008 Annual Report on the National Physical and Sensory Disability Database (Doyle *et al*, 2009) indicated that 13,848 people required assessment for therapeutic intervention and rehabilitation services, while 1,864 people were assessed and placed on a waiting list for these services. This database does not, however, look specifically at those needing neuro-rehabilitation and does not capture cognitive behavioural difficulties experienced by people with neurological conditions. These broad figures do not offer any accurate picture of the nature of disability and the level of care that this may require. Challenges are therefore evident in quantifying the incidence of people requiring neuro-rehabilitation services.

Challenges for neuro-rehabilitation

Society has changed dramatically over the last couple of decades. Factors such as increased life expectancy, a growing older population, rapid inward migration and constant advances in technology have led to Ireland becoming more socially and culturally diverse. Advances in medicine and related fields mean that there are more people surviving with greater levels of disability. Changing family structures and patterns mean that the numbers of lone parents have increased, while extended family support structures can no longer be assumed to exist for all service users.

All these societal changes hold significant implications for the planning and delivery of health and care services, including rehabilitation services. Most people with disabilities prefer and expect to remain in their own homes, wherever possible, and receive care and support services locally. This brings challenges to the health system, both in terms of delivering an appropriate quantum and quality of care, as well as in promoting independence through provision of cost-effective assistive devices that reduce barriers to participation in society. At the same time, provision of personal care and support by extended family members cannot be taken for granted.

While the majority of people with neuro-rehabilitation needs may be enabled to live at home or within a range of supported living settings, the complex care and treatment needs of a significant number of service users with neurologically disabling conditions may only be best met in more specialised residential settings. The respite needs of those people living at home and their families are additional factors for consideration. Strategic, coherent, evidence-based planning around capacity, needs and resourcing at appropriate levels of care is vital if people needing services are to move in and out of the continuum without experiencing undue delays, and without the system itself becoming 'blocked' at different levels. Deficit of data around incidence and anticipated care needs presents a major challenge in assuring such planning.

Neuro-rehabilitation encompasses a range of diverse conditions and settings. To reiterate the WHO definition given on page 19, neuro-rehabilitation is '*a problem-solving process in which the person who experiences a neurological impairment or loss of function acquires the knowledge, skills and supports needed for their optimal physical, psychological, social and economic functioning*'. Adopting this definition for the present policy implies that an extensive network of activities and supports should be available to service users in working towards optimal physical and other outcomes. In a climate of financial pressure and continual stretching of available resources, there is an imperative for the health system to define and consolidate its own core business around addressing health needs, while at the same time forging, maintaining and nurturing links with other agencies and sectors that have the statutory responsibility to provide appropriate support services, such as housing and transport. While this is a challenge for the health system, such confirmation and common understanding of respective roles and remits not only presents positive potential for collaborative cross-sectoral working towards shared aims, but also offers opportunities for the health system to examine core functions and remit in neuro-rehabilitation and to promote new ways and protocols of delivering quality, person-centred, cost-effective services.

Increased knowledge and awareness of neurological conditions and their treatments, together with rapid technological advances, mean that service users express heightened expectations of care and associated outcomes. It is a real challenge for the health service to balance such expectations against a finite amount of resources within which services are delivered. This highlights the critical importance of evidence-based planning and associated utilisation of resources towards effecting quality service delivery. Similarly, medical advances

in surgery and anaesthesia have resulted in improved survival rates for those who have experienced severe neurological injury or illness, resulting in an increased need for neuro-rehabilitation. This increased demand should be measured not in numerical terms but in terms of greater complexity and dependency on care – with significant implications for long-term neuro-rehabilitation planning.

While the causes of many neurological conditions may be unavoidable, the level of morbidity arising from traumatic incidents, such as road traffic accidents and violent assaults, is of great concern. Notwithstanding the immense impact of such events on societal well-being as well as on the individual's health status, this places greater demands on the health system. A population health approach around prevention of accidents and promotion of health and well-being is of great relevance in this regard.

Impacts of neuro-rehabilitation

The health and social gain to individuals and communities of people requiring neuro-rehabilitation services being supported to restore function and participate actively in all aspects of societal living cannot be underestimated. Promotion of effective neuro-rehabilitation should therefore be acknowledged as a sensible, practical, long-term national investment. At an individual level, the impact of not receiving appropriate or timely neuro-rehabilitation leads to deterioration in function and numerous associated physical and psychological sequelae, necessitating increased levels of re-admissions to acute hospitals and an unnecessarily increased reliance on costly healthcare. The inability to gain admission to neuro-rehabilitation care leads to such consequences as 'bed blocking', delayed discharges to appropriate settings and corresponding limitations in ability to deliver neuro-rehabilitation in a planned anticipatory manner.

Economic case for neuro-rehabilitation

Health economics can be defined as the broad application of economics to the health sector. Among its concerns are analysis of the costs and consequences, on individuals and society, of alternative ways of improving health and of delivering the various health programmes that include preventive, curative and rehabilitative health services (Mills and Gilson, 1988).

Research on the health economics of neuro-rehabilitation indicates that there are significant and substantial benefits to be had from these services and, in many instances, they make sound economic sense. Unfortunately, however, the evidence base in this area is small, but growing. In fact, it has been quite recently stated that the study of cost-effectiveness in rehabilitation medicine is in its infancy (Cardenas *et al*, 2001), an opinion supported by the fact that currently in the UK's NHS Economic Evaluation Database of 24,000 health economics

abstracts, only about 3% actually relate to rehabilitation. Of the studies to date reporting on the health economic aspects of neuro-rehabilitation, the earlier work has limitations that require careful interpretation. This is because most have some degree of significant methodological problems in study design, arising from factors such as non-inclusion of a comparison group, being of small size or short duration, or failing to include all relevant costs and other factors (McKenna *et al*, 1992; Byford *et al*, 1995; McGregor *et al*, 1997; Cardenas *et al*, 2001).

Although the information deficit is disappointing, it is perhaps not surprising considering that neuro-rehabilitation services have inherent complexities that do not lend themselves easily to rigorous economic analysis. For example, not only is there wide variation in neurological conditions and clinical presentations, but also the rehabilitation services involve multiple disciplines and multiple treatment components and there are challenges in assessing a range of outcomes over long periods of time. Despite these challenges, the methodology for health economic analysis is now sufficiently well developed to be applied in rehabilitation research (Drummond *et al*, 1987; Udvarhelyi *et al*, 1992; McGregor *et al*, 1997; Turner-Stokes, 2007a). The available evidence, some of which is presented below, indicates that significant economic benefits can accrue at individual level and at societal level from appropriate neuro-rehabilitative services.

Community-based rehabilitation teams

An important theme arising in a review of the current health economics literature is the value of community-based rehabilitation teams in the provision of rehabilitation services. The evidence suggests that these teams can provide models of care that surpass conventional hospital-based services in economic efficiency; also that they are as effective and achieve higher levels of patient satisfaction. This has been demonstrated among patients with stroke and multiple sclerosis – as described in the following section, which presents an overview of some of the health economics evidence on specific conditions, selected as being likely to represent the main issues that arise across the spectrum of conditions that can benefit from neuro-rehabilitation.

Stroke neuro-rehabilitation

The research evidence indicates that stroke rehabilitation is cost-effective. Much of the health economics research in this area looks at various models of care for acute stroke and the main findings are:

- care in dedicated stroke units is more cost-effective than care in a general hospital unit;
- there is short-term evidence that patients with severe stroke may benefit significantly from regular interdisciplinary stroke team conferences at no significantly increased costs;
- planned early discharge with domiciliary rehabilitation can be highly efficient, as can other models of community-based services for selected cohorts.

In a review of 22 studies, it was concluded that care in dedicated stroke units is more cost-effective than care in a general hospital unit (Cardenas *et al*, 2001). A randomised control trial (Kalra *et al*, 1993) found that patients allocated to a stroke rehabilitation ward had improved outcomes and reduced hospital stay without increased therapy time. Kramer *et al* (1997) found greater functional recovery in stroke patients admitted to a rehabilitation facility compared to skilled nursing units; the differences in outcomes were attributed to the greater comprehensiveness and intensity of rehabilitation services provided at the rehabilitation centres. The skilled nursing units in Kramer *et al*'s study rarely provided any psychiatric care, psychology services or recreational therapy.

A study in Japan (Yagura *et al*, 2005) demonstrated the cost-effectiveness of hospital interdisciplinary rehabilitation teams. It found that patients with severe stroke appeared to benefit significantly from regular interdisciplinary stroke team conferences in a stroke rehabilitation unit and had an improved discharge disposition, compared to patients randomly allocated to a general rehabilitation ward. Patients in each group received the same rehabilitative interventions and there were no significant differences in their hospitalisation costs.

Regarding planned discharges from hospital following acute stroke, a systematic review of randomised control trials with economic analysis was carried out comparing usual stroke care to early hospital discharge and domiciliary rehabilitation (Anderson *et al*, 2002). Seven published trials involving 1,277 patients were identified and the pooled data showed that a policy of early hospital discharge and domiciliary rehabilitation reduced total length of stay by 13 days. There was no significant effect on mortality or other clinical outcomes. The overall mean costs were approximately 15% lower for the early discharge intervention (US $9,941) compared to usual care (US $11,390). Included in a review by Brady *et al* (2005) was moderate evidence that among stroke patients with mild or moderate disability, early supported discharge was less costly than routine care.

A recent study looking at community-based rehabilitation for young stroke patients (Bjorkdahl *et al*, 2006) compared home rehabilitation to rehabilitation at day clinics. The clinical analysis showed that the two rehabilitation strategies were substantially equivalent at the end of follow-up, but that rehabilitation provided in the home resulted in a 42% reduction of total costs (€1,830 in the home group compared to €4,410 in the day clinic group).

A good example of the way forward in achieving robust evidence on cost-effectiveness can be seen in a recently reported small pilot study, conducted alongside an ongoing multi-centre randomised controlled clinical trial (Tay-Teo *et al*, 2008). This study assessed the cost-effectiveness of very early mobilisation of acute stroke patients in addition to standard care, compared with standard care alone. At 3 months, the mean per patient total costs were 38% lower for the very early mobilised patients (Aus $13,559 compared to Aus $21,860 for the standard care only patients) and at the 12-month follow-up the mean total cost difference was 41% lower in the very early mobilisation group. The authors inferred that the increased cost of more intensive therapy provided to very early mobilisation

patients was compensated by their shorter length of hospital stay and that the main differences in costs were due to less demand for both in-patient and community services.

Acquired brain injuries neuro-rehabilitation (other than stroke)

The economic studies on neuro-rehabilitation for patients with acquired brain injuries, other than stroke, highlight the significant financial resources required for their care, as well as the potential substantial and significant benefits to be had from rehabilitation, even among the most severely injured.

In a critical review of the literature on traumatic brain injury, Ricker (1998) concluded that in circumstances where rehabilitation was conducted appropriately and ethically, it can be worth the cost. A recent review of multi-disciplinary rehabilitation provided further evidence of efficiency (Turner-Stokes, 2008). Among the reported benefits of rehabilitation from the various studies were the positive impact on functional outcome with reduced need for supervision, improved vocational reintegration and increased ability to perform activities of daily living. Many of these studies clearly demonstrate significant cost-savings in terms of reduced care costs post-rehabilitation.

In fact, the main body of evidence that demonstrates the economic benefits of neuro-rehabilitation reports outcomes mainly in cost-saving monetary terms, arising from the savings in care services. An example of such work is a 6-year cohort study of patients with acquired brain injury admitted to a tertiary referral centre (Turner-Stokes *et al*, 2006). All patients in each of the three graded categories of dependency showed a significant reduction in dependency and ongoing care costs: the mean reduction in weekly cost of care was greatest in the high-dependency group (at £639 per week); the reduced mean costs for the medium-dependency group was about half this amount (£323 per week), while it was about one-sixth this amount for the low-dependency group (£111 per week). Despite their longer length of stay, and resultant higher treatment costs, the time taken to offset the initial cost of rehabilitation was only 16.3 months in the high-dependency group. It was 21.5 months for the medium-dependency group and 38.8 months for the low-dependency group.

A further study (Turner-Stokes, 2007b) examined longer-stay rehabilitation in a small group of complex patients. It demonstrated that the additional investment in this group was offset by long-term savings in the cost of care in a relatively short period.

The evidence also clearly demonstrates that the earlier rehabilitation services are introduced, the better are the expected outcomes and the lower are the future costs in present value terms (Cope and Hall, 1982; Ricker, 1998; Wood *et al*, 1999; Worthington *et al*, 2006). Among these studies is an evaluation of a community-based post-acute brain injury rehabilitation programme exploring the social outcome achieved by 76 persons with serious neuro-behavioural

disabilities, such that they were unable to live independently (Wood *et al*, 1999). Findings demonstrate that those availing of the programme within 2 years of their injury showed the greatest reduction in care costs; among these, following an average of 14-months' rehabilitation, the reduction in care costs per person amounted to just over 30% of the cost of rehabilitation for 1 year. The calculations for the group of persons entering the programme 2-5 years post-injury showed a less dramatic, but significant reduction in care costs. Among the persons commencing the programme more than 5 years post-injury, modest saving in care costs were noted.

A recent study by Worthington *et al* (2006) demonstrates that significant savings in costs of support could be made well beyond the period when natural recovery could be considered to be contributing to outcome. Regardless of the initial outlay on rehabilitation, this small study shows that expenditure on neuro-behavioural rehabilitation generally pays for itself within 2 years. In general, it was found that the shorter the time period between the brain injury and rehabilitation, the greater the savings:

- for people admitted within 12 months of injury, the cost-savings per year were £53,108, with estimated lifetime savings of between £1.1-0.8 million;
- for those admitted within 2 years of injury, the annual cost-savings were £34,788, with estimated lifetime savings of £0.7-0.5 million;
- for those seen more than 2 years after injury, the annual cost-savings were £26,860, with lifetime savings of £0.5-0.36 million.

There has been very little research into the cost-effectiveness of the various components of neuro-rehabilitation in brain-injured patients. A study that used multiple regression analysis to predict the functional gains and efficiency related to type and intensity of service did find that only psychological intensity correlated with cognitive outcomes in traumatic brain injury (Heinemann *et al*, 1995).

A fundamental challenge facing researchers in the area of acquired brain injuries arises from the lack of comprehensive cost-of-illness studies that address both the direct and indirect costs of such injuries. For example, a recent review of 12 European countries on the cost of traumatic brain injury demonstrated that the economic evidence on this is presently very scarce, with the available information mostly related to hospital treatment, which is known to constitute a relatively small component of overall costs (Berg *et al*, 2005). An additional challenge is that cost-effectiveness studies of the rehabilitation services for brain-injured adults should be considered in the broadest terms, beyond return to work, with outcomes measured across a range of socially meaningful domains (Turner-Stokes, 2007b).

Vocational rehabilitation for brain-injured patients

There have been a number of studies analysing the resource consequences of vocational rehabilitation programmes developed to help individuals with traumatic brain injury to obtain or retain employment. These studies have found that such programmes are economically efficient. In one group, it was estimated that the

projected client's earnings would exceed the programme's total costs and result in a positive net gain for tax payers after approximately 2.5 years (West *et al*, 1991; Wehman *et al*, 1994). In another study, the total earnings of the successful participants exceeded the programme cost four-fold (Abrams *et al*, 1993). A more recent study in the UK of a vocational rehabilitation programme demonstrated that it was effective in enabling participants with severe acquired brain injuries to return to paid employment (Murphy *et al*, 2006). Of the 232 selected participants, a total of 41% were discharged into paid competitive employment, with a further 16% gaining voluntary work and 15% taking up mainstream training or education.

Spinal cord injury neuro-rehabilitation

There is evidence to show that specialised spinal cord injury centres are cost-effective compared to general hospitals. Length of stay was found to be twice as long for patients in a general ward (Heinemann *et al*, 1989) and fewer complications and shorter length of stay were found with earlier admissions to specialised units (Oakes *et al*, 1990). However, the intensity of services as a factor in functional outcome has not yet been determined for spinal cord injury. A small number of studies have compared the cost of providing care at home compared to care in a nursing home: findings show that significant economic gains are associated with community-based programmes, which were due in part to increased earnings as a result of vocational training (Cardenas *et al*, 2001).

Multiple sclerosis neuro-rehabilitation

For multiple sclerosis neuro-rehabilitation, some studies have shown that multidisciplinary teams can be cost-saving, such as the community-based team evaluated in Newcastle-upon-Tyne (Ward *et al*, 2009). The savings arising from reduced hospital bed usage and reduced out-patient visits due to the multidisciplinary team involved were equivalent to the cost of the team itself, thereby rendering the whole team cost-neutral.

Another study examined costs, clinical outcomes and quality of life of home-based care to patients with multiple sclerosis, in comparison with standard hospital care (Pozzilli *et al*, 2002). It found that home-based care proved to be appropriate and cost-saving for patients – the total costs per patient were 55% higher in the hospital-based care control group (€2,265) compared to the home-based management intervention group (€1,443). In the sensitivity analysis, home-based management remained superior, with the cost-savings over the traditional hospital-based care ranging from €2,086 (best case scenario) to €234 (worst case scenario).

Main benefits of Physical and Rehabilitation Medicine Specialists

In a report summarising the national position of rehabilitation medicine in the UK (BSRM, 2007), the British Society of Rehabilitation Medicine noted several ways in which the Physical and Rehabilitation Medicine (PRM) specialty made a significant economic contribution to society:

- By preventing costly complications (e.g. skin sores, joint contractures and fractures), thus reducing expensive, avoidable hospital admissions. Facilitating self-care tasks is also a skill learned in the rehabilitation process by patients and this reduces dependency and thus the burden on the healthcare system.
- By coordination of complex discharges (where appropriate sub-acute facilities and services are available), PRM specialists reduce the duration of admissions in acute services. This builds well on the proven ability of PRM specialists to work across disciplines and between agencies.
- Many people with complex disabilities are frustrated by the barriers they face in retaining or regaining employment. The specialist medical expertise of PRM specialists helps these individuals achieve their full potential for economic participation.

Key messages from the consultation process

Submissions were sought from the general public, patient/user groups and service providers in order to ensure that this neuro-rehabilitation policy would be informed by as wide a range of views as possible. An advertisement was placed requesting ideas, proposals and views on neuro-rehabilitation services and 77 submissions were received from individuals and groups, including service users, families and carers, service organisations, national advocacy bodies, individual professionals, non-statutory sector service providers, HSE service providers, umbrella groups representing service users, public representatives and national professional fora (*see Appendix 2 for list of submissions*).

The consultation process offered a wealth of information and insight into the reality of life for those needing neuro-rehabilitation services. Learning from this exercise has not only informed development of this report, but will also serve to inform ongoing efforts in all aspects of rehabilitation service provision. To this end, all information gathered during the consultations has been captured and analysed.

A detailed review was carried out by members of the Working Group on all 77 submissions and their content analysed, drawing out the key themes and main messages for this policy. Certain key messages were resonant themes in submissions and are highlighted here in order to reflect their importance in informing overall development, direction and approach of this policy:

- '*The heartache started on their discharge to the community … I have done needs assessments on many groups of people, but this was the one area where I felt deeply affected by their total loss and inability to traverse the healthcare system once discharged from hospital. Also, they were traumatised by the lack of understanding on the part of many healthcare professionals*.' **Dr. Regina Kiernan, Consultant in Public Health Medicine**
- '*Rehabilitation services should be based on need, regardless of age*.' **Neurological Alliance of Ireland**
- '*There is a limited access to therapy in the community and rehabilitation teams comprising a range of disciplines, including occupational therapy, speech and language therapy, psychology, nursing, rehabilitation assistants, social work, creative arts therapists. Teams do exist, but work independently of each other, are scattered, incomplete and insufficient for need*.' **Richard Stables, Headway**
- '*Rehabilitation services and supports play an important role in the lives of people with disabilities. Effective rehabilitation will enable these individuals to eventually return to, and participate in, community life. This will lead to greatly improved quality of life for the individual, with resultant health and social gain*.' **Jacinta Dixon, Disability Federation of Ireland**
- '*AOTI [Association of Occupational Therapists of Ireland] recommend the establishment and expansion of post-acute rehabilitation units, both nationally and regionally. This would maintain the speciality services needed for those people who require highly specialised and high-intensity therapy to reach their maximum independence, while also providing better access for those at local or regional level to avail of in-patient rehabilitation services*.' **Association of Occupational Therapists of Ireland**

Submissions from **organisations that provide services** shared a common focus on systemic elements, such as increased funding, dedicated resourcing and provision of ongoing training in order to address service needs effectively. The need to achieve integrated service delivery and mechanisms of effecting this were common themes, while many suggestions were also made about enhancing the quality of services and improving the utilisation of existing resources. The shortage of neuropsychologists was most frequently mentioned in submissions. Community-based therapists (occupational, physiotherapists, and speech and language) were noted as particular barriers to offering timely and effective neuro-rehabilitation. Strengths and weaknesses of the existing system were outlined, with proposals on how to close gaps in provision and how to work towards a more coherent system of neuro-rehabilitation service delivery.

Views of **service users** were often more personal in nature, reflecting their experiences in attempting to access rehabilitation and their frustrations when encountering barriers in this process. Lack of integration of services, reports of inequities, delays and lack of insight among staff on the person's needs were highlighted regularly. A sense of disempowerment permeated many submissions, together with feelings of anger and frustration on the lack of appropriate information and advice. The importance of clear information in a standardised

format in relation to eligibility to and availability of services was a recurring theme among service users. Many deplored the lack of such information, as well as the limitations in available supports to access services. Many barriers were reported as existing for people of different age groups, with children and their parents appearing to encounter particular obstacles in accessing appropriate services at the optimal time. Services were regarded as rigid and unresponsive, with age or diagnosis often appearing to be the criterion for access, rather than individual need.

Key issues identified during the consultation process by **both service users and service providers** highlighted gaps in a continuum of neuro-rehabilitation services, with specific reference to:

- a lack of appropriate step-down facilities for people discharged from rehabilitation;
- absence of rehabilitation services in many residential facilities and nursing homes;
- lengthy delays in effecting necessary house adaptations;
- uneven service distribution across the country, together with varying approaches to service provision, emerged as a further major factor leading to inequities of access to treatment and support services.

Another issue identified by **both service users and service providers** was the need to involve families, carers and other relevant people in the neuro-rehabilitation process. For service users in particular, this was seen as a critical factor in facilitating engagement with social and recreational spheres of activity, as much as in supporting basic daily living tasks. Indeed, the importance of social activities and purposeful occupation as a means of enhancing quality of life was viewed as an integral component of successful rehabilitation. This is an essential factor – but one that may easily be overlooked – for consideration in developing any model of neuro-rehabilitation service provision.

The inadequacy of provision of essential aids, appliances and assistive technology was cited as hampering optimal independence. The potential of assistive technology – in supporting the service user to exert autonomy, live as independently as possible and overcome barriers to participation in activities – has not always been optimally harnessed. Adaptations to housing, together with provision of appropriate aids and assistive devices, can be a cost-effective means of empowering individuals and providing enhanced quality of life (*see Chapter 3*).

At the same time, it must be said, good practice in many services was acknowledged by those who made submissions. Understanding was also expressed about the difficulties encountered in moving towards an integrated model of service provision, with many realistic, constructive suggestions made on how to address these. These observations, suggestions and recommendations have been analysed and have informed the development process of this policy.

3. Purpose, scope and vision of Neuro-Rehabilitation Policy and Strategy

Purpose and scope

The need for a national rehabilitation policy, which would allow for a clear consistent framework for planning and implementing quality rehabilitation services, has been acknowledged in Ireland. The National Health Strategy published by the Department of Health and Children in 2001, entitled *Quality and Fairness – A Health System for You*, signalled a new direction in planning and delivery of health services in Ireland. It defined a framework of service delivery where the principles of equity, accessibility, quality and accountability are fundamental to all aspects of planning, development and evaluation of services. Its explicit aim is a health system that '*is there when you need it*' and that '*supports and empowers you, your family and community to achieve your full health potential*'. Intrinsic to such an approach is the acknowledgement that each individual is at the centre of the planning and delivery system within health and that such people must be empowered to participate in this as equal partners.

One action identified in the National Health Strategy was the development of a national action plan for rehabilitation.

The commitment made in the National Primary Care Strategy, *Primary Care: A New Direction* (Department of Health and Children, 2001b) – to building primary care as a key vehicle in addressing the majority of health needs – is closely aligned to the objectives of the National Health Strategy. This shift in approach demands a reorientation in service provision for all people with neuro-rehabilitation needs, with increased attention being focused on building capacity at community level to cater for the care and management needs of this cohort.

While a number of initiatives were undertaken within the former Health Boards on the development of strategies addressing rehabilitation needs, the establishment of the HSE as a unitary body has facilitated a more coherent approach to the development of a national strategy in this area. Ongoing restructuring of the HSE also provides opportunities for the development of an integrated model of provision, which would ensure equity and consistency across the country. The values espoused in the HSE's *Transformation Programme 2007-2010* further cement and confirm the importance of a truly person-centred approach, where each individual receives services based on need and where he or she is an active participant in decisions relating to the management of their condition and health needs (HSE, 2007). Involvement of families and carers is also central in this approach. The HSE Value Charter reflects a key shift in approach since it explicitly commits to such values as actively respecting the views of service users and provision of high-quality, reliable, person-centred care, delivered as close to home as possible. Thus, the HSE's Transformation Programme is underpinned by

the principles contained in the National Health and Primary Care strategies, and acts to further promote and support an integrated model of service delivery for all service users, including those with neuro-rehabilitation needs (HSE, 2007).

Rehabilitation encompasses a range of conditions and associated methods of care and management. Many of the rehabilitation needs of patients are dealt with via parallel processes, including the National Cardiovascular Health Policy 2010-2019. Such strategies may usefully be aligned with this policy for neuro-rehabilitation. At the same time, however, care is taken in this report to avoid duplication and to ensure a clear focus is directed on neuro-rehabilitation. A key principle underpinning this model is that the appropriate competencies, consistent with individual needs, must be accessible to each person. However, this does not mean that the structure of provision is condition-specific.

Vision: A framework for the provision of future neuro-rehabilitation services

Against a backdrop of increased pressures on the health services, coupled with a climate of reducing resources, it is still incumbent on the health services to hold a realistic vision of a system where people with a neurological or other physically disabling condition will have timely access to the appropriate continuum of neuro-rehabilitation services as near as possible to their home and community setting, so that they can maximise their functioning, independence and participation in both the social and economic life of their family and community. These services should be truly integrated from local to national levels and within geographical areas. This can best be assured where clear protocols are developed and implemented consistently, underpinned by an appropriate governance framework.

During recent years, significant energy and focus have been directed at increasing capacity within the health and personal social services, facilitated primarily by the injection of new development funding. Given the current economic downturn and its consequential impact on further capacity-building, the initial focus of any new strategy has to be on reconfiguration of current service designs and structures, with increased emphasis on flexible work practices and professional boundaries, further development of personal and professional competencies, and more collaborative team-working. Such a strategy will enable a more rational approach to service development.

This policy will outline a strategy or vision for future neuro-rehabilitation facilities in Ireland in the longer term based on international experience. While it may not be feasible in the current economic climate to implement this vision in the shorter term, endorsement of this policy offers a valuable opportunity to explore current ways of service delivery and to develop creative and innovative mechanisms aimed at improving and strengthening the system. The focus in the interim should be on effective and efficient delivery of services in settings that are the most appropriate to the individual, in a timely fashion and which offer best value for money.

Underpinning a vision of neuro-rehabilitation is the aim of developing a strategic framework that supports the creation of a coordinated, integrated, flexible response to the many varied neuro-rehabilitation needs of service users at all levels of care. This policy will therefore attempt to promote a model of service delivery that seeks to create a chain of neuro-rehabilitation – from acute neuro-rehabilitation to long-term neuro-rehabilitation support in the home and community. It sets out a vision of care that is as close as possible to people's homes and that enables service users and their families to participate to the greatest extent possible in their own neuro-rehabilitation programme. This will include attention to overall service needs analyses and a detailed mapping of existing service provision to ensure that existing resources are efficiently deployed and coordinated to meet the neuro-rehabilitation needs of all patients (*see Chapter 5*). The analysis should serve to inform and facilitate efficient utilisation and coordination of existing resources, as a means of addressing neuro-rehabilitation needs within a modern, responsive service delivery framework. This will then establish the conditions for future investment in the development of services in the medium term. This approach will require more cross-agency collaboration, increased team-working and participation by the person's natural and informal supports as equal partners in the support framework.

The development of this National Neuro-Rehabilitation Policy is therefore timely and will guide coherent and effective service development in the future. It will also provide strategic direction and support for more effective coordination of existing services delivered by the State in partnership with non-governmental organisations. The scope of the policy is therefore specifically directed at those individuals who are likely to require a spectrum of neuro-rehabilitation – from an initial intensive period of neuro-rehabilitation or recurring intermittent periods of intensive neuro-rehabilitation, to long-term maintenance neuro-rehabilitation in order to restore or maintain the individual's maximum personal autonomy and/or well-being.

This policy reviews the evidence as it applies to a number of key neurological conditions in order to outline a framework for neuro-rehabilitation care. This framework proposes that services be provided on an integrated basis from enhanced primary care teams, to community-based neuro-rehabilitation teams, to regional in-patient hospital care, and, finally, through national specialist centres.

In order for this framework to be developed, the HSE will need to put an appropriate structure in place at national and regional level, with key executive and clinical leads. Those tasked with these responsibilities will need to be supported by designated personnel at regional level. The primary task at regional level will be to build on the service mapping exercise contained in this report (*see Chapter 5*) to accurately identify existing resources available in both hospital and community settings in each region that can be integrated into a coherent network of service provision. This network of provision will incorporate and build on existing condition-specific expertise and create a model of provision that is accessible by all those who require neuro-rehabilitation services, regardless of

primary diagnosis. This will require reconfiguration of existing statutory and non-statutory sector provision, consistent with the framework being proposed (*see Chapter 7*). It is expected that this task will take up to 3 years for implementation and consolidation. This process will uncover some gaps in specific therapeutic capacity, as well as significant inequity in service provision across the country, which will need to be addressed incrementally. However, it is critical that this reconfiguration is inclusive of all service provision – both HSE direct and non-statutory providers – which will challenge existing organisational and professional boundaries.

A vision for future investment in and development of neuro-rehabilitation services will build on the framework of care and supports as outlined in this policy and will strengthen the integrated service model developed through the initial implementation of this policy.

Rehabilitation the way it should be – Local, Individualised, Timely and Integrated (LITI)

- **Local** – ***Rehabilitation where I need it***: The person served should not have to travel far to access services that are deemed to support their inclusion and participation in their local communities. As far as possible, assistive technologies, including exercise machines, should be located in the home and their use integrated into daily activities.

- **Individualised** – ***Rehabilitation the way I need it***: Individualised services should be tailored to the needs of the individual, taking into account their environment, their condition and its likely future development.

- **Timely** – ***Rehabilitation when I need it***: It is well accepted that for rehabilitation to be effective, timely access to the appropriate services and supports is critical. Conversely, when an individual's condition deteriorates by virtue of not being able to access such services in a timely manner, the consequences for both the individual and the system are inherently negative. No part of the deterioration should be attributable to delay or failure to anticipate need.

- **Integrated** – ***Rehabilitation should I need it***: There is clear evidence that in many instances needs assessment is carried out by those tasked with delivering services and as such may only reflect the needs that can be met. However, the needs assessment must be holistic and clear pathways must be identified to facilitate easy access. This can best be achieved when service structures are integrated. This does not require that all services are delivered in the same setting, but it does require clear protocols to be developed and implemented consistently along the continuum of services.

For individuals with long-term conditions, an approach that is person-centred has been found helpful elsewhere (Department of Health [UK], 2005a). For the individual, independence is maximised, leading to improved quality of life and economic participation. For society, the burden of care is reduced – avoidable, expensive and long or frequent hospital admissions are significantly reduced. Indeed, tax revenue might also be increased (Department for Work and Pensions [UK], 2005; Health, Work and Well-being [UK], 2009). Based on these insights, strategies along the following lines should be implemented and further developed, tailored to the Irish context:

- **Case management approach**: Identify intensive users of unplanned acute and secondary care services. Appoint a case manager (typically in the community) who will anticipate, coordinate and join up health and social services to meet, and thus reduce, the burden of care.
- **Disease-specific care management**: Provide people having a complex single condition or multiple conditions with a responsive (ideally local) interdisciplinary team, working to disease-specific protocols and pathways, to anticipate need, maximise independence and quality of life, and thus reduce the burden of care.
- **Supporting self-care**: Equip individuals having long-term conditions (and their carers) with the knowledge, skills and confidence to care for themselves proactively, effectively and as independently as possible.

In the medium term, after the initial period of reconfiguration and integration of existing provision has been completed, it will be appropriate and timely to enhance current service provision in a number of ways to ensure that the continuum of care is strengthened for all people needing neuro-rehabilitation services. Areas that will need early consideration for future investment are additional medical rehabilitation specialists and neuropsychologists. Existing community-based neuro-rehabilitation teams will need to be strengthened if the LITI criteria (*see above*) are to be met. This will enable community teams to develop and retain specific expertise in the management of specific conditions and aspects of neurological damage, while also ensuring that the needs of all those requiring neuro-rehabilitation are met appropriately and in a timely manner. Over time, specialists in medical rehabilitation will need to be appointed to each of the 4 HSE Regions and they will lead the further enhancement of services at regional and community level, working closely with their neurologist and geriatrician colleagues. In the interim, those with specialist competencies will have to be a resource throughout the service structure.

While the focus of this policy is on the health and personal social services needs of people who require, or who can benefit from, neuro-rehabilitation, it is well established that the needs of such people may extend beyond the health services and, as such, a holistic or ‘whole system’ approach needs to be taken. Vocational services, for example, prepare the individual not just for integration back into the economic life of their community, but can also be a major contributor to their recovery. Similarly, provision of housing can be a core requirement for the person and, as such, those services must be accessed through the local authority. In a significant number of such cases, people will require health and personal

supports so as to sustain them in such accommodation, which comes within the remit of the health system.

Principles underpinning the policy

The consultation process undertaken for this policy proved valuable in informing and confirming the values and principles that should underpin it. These considerations are key to ensuring development of a policy that is attuned to the situation of people requiring neuro-rehabilitation and that provides a clear coherent framework to establish and respond to their needs.

In the context of neuro-rehabilitation services, the following principles should inform future service development:

- **Person-centred** – Including involvement of families and carers, with people being able to move 'up and down' the service pathway as needed.
- **Dignity and respect** – People should be treated with dignity and respect at all times.
- **Service user participation** – Service users' views and expertise in the management of their conditions are integral to service provision.
- **Responsive to need** – Services should be flexible in time and place to provide appropriate services at the right time and in the right place. Service users should have access to timely, ongoing, high-quality neuro-rehabilitation as they need it.
- **Integration** – This is a core component in delivery of quality services. Services at supraregional (national), regional and local levels need to work closely together to ensure a continuum of care and that expertise is shared across the system.
- **Close to home** – The ultimate objective of neuro-rehabilitation services is to enable the person served to re-engage with their family and community, and accordingly the support services needed must be provided as close as possible to the home.
- **Empowerment** – Individuals and their families should be empowered to achieve their full potential and to optimise their participation in society.
- **Variable needs and preferences** – Services must be organised, located and accessed in a way that takes greater account of the variable needs and preferences of the person served, as well as co-existing conditions such as visual and/or deaf and hard of hearing.
- **Active participation** – People served by neuro-rehabilitation services should actively participate in the planning, development and delivery of those services.
- **Equity of access** – There should be equity of access for service users irrespective of their age, degree of restriction or geographical location.
- **Live at home** – Service users should be facilitated to live at home where possible, i.e. through provision of assistive devices and technology as appropriate, and home adaptation where necessary. They should have access to personal care and support to maximise their ability to live independently and to participate economically and socially.

- **Access to information** – Service users, their families and their communities (including service providers) should be empowered and supported through ongoing access to information, advice and education so that they can be active participants in their own neuro-rehabilitation.

Responsiveness of the system

The changing and diverse needs of people requiring neuro-rehabilitation services demand a flexible dynamic health system, one that is responsive to differing needs and is able to address them in a timely appropriate way. Thus, the system should be capable of serving complex varied needs that are likely to change over time. Such a shift may necessitate evaluation of current roles and work practices across all settings and services where neuro-rehabilitation is provided, with a view towards extended opening hours for services, introducing more flexible working hours for staff, increasing teamwork and multidisciplinary practices, and developing and embracing more interagency collaborative working. All of these measures would allow for services to be delivered through a multidisciplinary approach and significantly improve quality of care, as well as reducing the burden placed on the people served and their families by virtue of having to attend at multiple settings and times to access services. Such a move towards improved integration of services and settings should impact positively on the experience of people accessing services. Continuity of care is essential to promote optimal outcomes and to prevent any avoidable deterioration in health status.

Reconfiguration of services and service provision

The Transformation Programme of the HSE is well underway, with the shift towards enhancing capacity of primary care now a key driver in reorientation of services. This move is designed to free up hospitals and designated supraregional settings so that they can deliver specialist complex treatment, while the majority of care that can be safely delivered at community level will be effected by established primary care teams, supported by community-based rehabilitation teams, working within designated geographical areas. Best practice mechanisms of collaborating with the range of non-statutory organisations delivering services at all levels should be pursued. This approach presupposes the building of capacity at community level to deliver services effectively. Clear identification of roles at different levels of care and strong links between primary care teams and specialist geographically based teams are essential to facilitate support and advice, as well as to nurture a shared collaborative approach to the needs of clients with more complex care needs. This can best be achieved by nationally defined care pathways and protocols that will clearly define (1) a catalogue of services/supports to be provided, including access mechanisms and care settings; and (2) clinical protocols for assessment, referrals, treatment and support of the person served along the journey.

Intersectoral collaboration and partnership working

Given the many interrelated factors impacting on quality of life of people needing neuro-rehabilitation, only some of which fall within the responsibility of the health sector, it is imperative that there is a 'whole system' approach in which each unit of authority commits to having clear policies and service protocols in place and that, where possible, there are joined-up and collaborative strategies and synergies in place that ensure that the experience of people being served is positive and beneficial. This is a key focus of the National Disability Strategy, launched by the Government in 2004 (Department of An Taoiseach, 2004), and is further strengthened in the Disability Act 2005, which requires that key Government departments publish Sectoral Plans in which they set out how they propose to meet their obligations to people with a disability. While there are islands of good practice in this area, it is still very much the practice that organisational and professional boundaries are key impediments to such an approach.

Support measures for attaining maximum independence

'*For most people, technology makes things easier. For people with disabilities, technology makes things possible. In some cases, especially in the workplace, technology becomes the great equaliser and provides the person with a disability a level playing field on which to compete*.'
Mary Radabaugh, former employee with **IBM Disability Support Centre**

Assistive devices (e.g. wheelchairs and dressing aids) and **assistive technology** (e.g. environmental controls and personal computers) enable people to maintain their health, to optimise functional ability and to facilitate care. They can have very positive impacts on the lives of users by:

- supporting independent living;
- enhancing quality of life though enhanced dignity, choice and control;
- increasing employment opportunities;
- enabling greater integration into mainstream education;
- reducing hospital stays;
- providing cost-effective solutions to augment and relieve other services.

The basis for the provision of these devices by the HSE is in the Health Act of 1970 and is subject to specific eligibility criteria. Such devices are an essential component of the rehabilitation journey for many individuals with neurological conditions. Throughout the submissions received for this policy, a pattern of frustration emerged regarding the lack of timely equitable access to appropriate devices and the consequent negative effect on rehabilitation outcomes.
The provision of these devices should be based, where possible, on the evidence available for their use and only by recommendations from appropriately trained healthcare professionals experienced in their use. Pertinent to their role, healthcare professionals should be aware of legislation regarding these devices.

It is essential that good management and governance systems are implemented locally, regionally and nationally for the management of these devices throughout their lifecycle, as recommended by the Irish Medicine Board. These systems should include preventative maintenance and repair management. In this regard, the Working Group for this policy understands that the HSE is in the process of compiling a medical device/equipment management policy.

Procurement and recycling of these devices, together with contracts for repair and servicing, should be reviewed at a regional and national level in a timely manner to ensure financial efficiencies. Consumer panels should be an essential component of these processes. Users provide essential feedback on the effectiveness of products, the efficiency of maintenance and repair services, and user requirements. Models of consumer panels are used though the United Kingdom.

It is also critical that individuals have access to **appropriate seating systems** at all stages of rehabilitation. Poorly prescribed seating can affect a person's swallowing, speech, breathing and ability to engage in everyday activities, as well as causing contractures, skin break-down, pressure areas and pain. The Working Group is aware of a myriad of arrangements that exist whereby people can access assistive devices and technologies, and that in many instances the arrangements are competitive. In recent years, there have been increased numbers of dedicated seating clinics established at community level. These services have received very positive feedback since they are easily accessible and are staffed by appropriately trained personnel. They have also demonstrated good value for money. Regional assistive technology and specialised seating services are required for individuals with neurological conditions who have very complex needs. Regional clinics, with a multidisciplinary team including clinical engineers, should provide outreach, education and training to local services. Pathways between local and regional services need to be established and access to regional services should be based on need rather than specific diagnoses.

Standards in the area of prescribing wheelchairs and other devices need to be developed and protocols around the timing of assessment and delivery of devices need to be established. In the area of assistive technology, recent initiatives have demonstrated that the trialing of devices prior to selection has resulted in more successful device selection and increased cost-effectiveness.

Special augmentative aids, such as picture and symbol communication boards and electronic devices, are available to help people express themselves and to improve comprehension. Such **augmentative and alternative communication** (AAC) aids provide people with a means of expressing their thoughts, needs, wants, opinions, concerns or worries. People with severe speech or language problems rely on AAC to supplement existing speech or replace speech that is not functional. Helping people to communicate obviously improves their quality of life and facilitates their involvement and integration into home, school/work and community environments. The funding of AAC should be prioritised and be of equal value as other assistive devices. In addition, the prescribing of AAC devices should be integrated with other technology services.

Key points

- Assistive devices and assistive technology should be accessible in a timely and equitable manner.
- Healthcare professionals who prescribe these devices should be appropriately trained.
- Seating clinics are required at a primary care level and assistive technology and specialised seating clinics at a regional level.
- Current arrangements between local, regional and national provision need to be reviewed.
- Robust management and a governance system for these devices need to be established.
- Procurement processes should be reviewed to ensure financial effectiveness.
- Consumer panels should be key stakeholders in the procurement process.
- Asset tagging systems need to be implemented.
- Loan services, particularly in the area of assistive technology, are essential.

Data collection

It has been acknowledged that data on the profile, needs and outcomes for all aspects of neuro-rehabilitation services are very limited. In some cases, there is a total absence of data. If the system is to meet its obligations to people with a neurological condition, it is critical that formal structures and processes are put in place to gather such data in a consistent way so that evidence-based planning, monitoring and evaluation of interventions can be progressed. In this context, significant investment has been made in the development of a number of databases within the health system that are intended to capture key information/ data so as to aid service planning and provision for people with disabilities. These databases should be reviewed so that they can be integrated into a single system that captures data as required for people with disabilities, including those with neuro-rehabilitation needs. The National Health Information Strategy (Department of Health and Children, 2004) provides a framework for the more effective collection and application of data.

Specialist leadership

In line with the models of clinical directorships and clinical care programmes, service reconfiguration, efficiency and improved service delivery will be driven by ‘clinical leadership’, a term used here to include all those who have a role in contributing to the rehabilitation cycle. This leadership needs to come initially at national level, tasked with the development of protocols which, in turn, need to be implemented consistently across the whole system. In the UK, for example, in implementing the National Service Framework for Long-term Conditions, rehabilitation medicine is the lead NHS resource for most quality requirements.

4. Strategic context for development of Neuro-Rehabilitation Policy and Strategy

Roles and functions of key statutory bodies

The Department of Health holds responsibility for the development of policy, evaluation of the performance of service delivery in respect of existing policies and the provision of a legislative framework to facilitate and support the development of health and personal social services. The Department's *Statement of Strategy* for the period 2008-2011 outlines its strategic actions priorities. This document reflects obligations defined in the current national social partnership agreement, *Towards 2016* (Department of An Taoiseach, 2006), including commitments to primary care services, mainstreaming of services and the enhancement of community-based care. The areas of disability and mental health are highlighted and high-level objectives have been set.

The Health Service Executive (HSE) was established in 2005 as a single unitary body holding statutory responsibility for the delivery and management of health and personal social services across the country, within a budget allocated through the Oireachtas. The Health Act 2004 sets a framework ensuring accountability of the HSE to the Minister for Health. The National Service Plan, which is drawn up annually by the HSE, sets out the agreed nature and volume of health-related activity to be delivered against the allocated budget. The HSE's *National Service Plan 2009* contains a number of targets and indicators relevant to improving outcomes for people with neurological conditions (HSE, 2009a).

The development of this National Neuro-Rehabilitation Policy and Strategy should be viewed against a background of the Department of Health and Children's National Health Strategy (2001a), entitled *Quality and Fairness – A Health System for You*. This advocates a 'whole system' approach to improving health and social gain in Ireland. Guiding principles of equity, people-centredness, quality and accountability underpin its approach to the development of a health system that '*empowers you, your family and community to achieve your full health potential*', while it further emphasizes the importance of working across sectors to address the range of determinants impacting on health status. Such an approach is particularly relevant in neuro-rehabilitation.

This approach is mirrored in the HSE's *Transformation Programme 2007-2010*, with its vision of 'easy access, public confidence and staff pride' (HSE, 2007). The Transformation Programme is a key vehicle supporting the reorientation of services, with a central aim being one of ensuring access by service users to timely, appropriate and effective treatment and services. In this programme, the development of an *integrated health and social care model for Ireland* is central to future service development. This involves the development of hospital and community services that are integrated at all levels across the system. Such

integration is designed to facilitate service users in moving seamlessly through and along a continuum of care. In this model, services are developed and delivered as close to home as is reasonably possible. As stated by the HSE, '*Patients/clients in an integrated system are more likely to receive the type and quality of care they need, when they need it, in the most appropriate setting and from the most appropriate health professional. It also promotes greater accountability, transparency and value for money*'.

Integral to this health and social care model is facilitating more accessible, local service delivery through building and enhancing the capacity of primary and community services to address health needs at this level of care. This does not take away from the critical role played by specialist services in either acute hospitals or designated specialist rehabilitation facilities – rather, it allows for specialist care to be provided at this level, while care that could better be delivered at local level is devolved to primary and community level. New governance and organisational structures are presently being established as part of an overall plan towards enhancing integration and quality of care.

From a neuro-rehabilitation perspective, any reconfiguration must be compatible with these structures and processes. Neurological conditions may necessitate accessing a range of different clinical and support services, delivered by different agencies, along the continuum at different times and with varying degrees of frequency.

Ensuring high-quality service delivery is a key focus of the HSE's approach to provision of integrated health and social care. The appointment of a dedicated Clinical Directorate, located centrally, is a critical step towards achieving this objective.

The HSE is heavily reliant on its partnership with the non-statutory sector to provide essential services in the area of disability and rehabilitation service provision. Agencies in the non-statutory sector play a vital role in providing a range of services allied to neuro-rehabilitation. These services are provided on behalf of the HSE via funded service-level agreements. Services extend from specialised neuro-rehabilitation at a tertiary level of care to provision of home care and personal assistance within the homes of service users.

Those tasked with the implementation of this National Neuro-Rehabilitation Policy and Strategy must continue to engage with the non-statutory sector in the ongoing development of an integrated model of service delivery, ensuring that roles and functions are complementary rather than competitive. Breaking down organisational barriers between service providers and enhancing their partnership role with the HSE, the Department of Health and other key Government departments will ensure that available resources are mobilised for the optimal rehabilitation provision for all persons with neuro-rehabilitation needs.

This policy has been developed against a landscape of projected demographic change, renewed awareness of the diversity of factors affecting health status,

increased expectations about rehabilitation outcomes, a rapidly changing economic environment and a climate of reducing resources.

A large number of national and international legislative and social frameworks govern, inform and give direction to the development and implementation of this policy (*see below*). At the same time, a range of health policies, strategies, reports, reviews and approved service programmes have a direct bearing on the planning and development of a framework for delivery of neuro-rehabilitation services.

International legislative frameworks

There have been a number of international conventions that govern disability and rehabilitation. These include:

United Nations Convention on the Rights of Persons with Disabilities: This Convention came into force in 2008. It spells out obligations of the original 1948 UN Declaration of Human Rights in the context of modern understandings of disability. Articles 25 and 26 are relevant to the development of the current policy on neuro-rehabilitation (*see* www.un.org/disabilities/index.asp):

- **Article 25** deals with health on a relatively broad level, obliging States parties to eliminate discrimination on the basis of disability in the delivery of healthcare services.
- **Article 26** deals more specifically with rehabilitation, stating:
    1. States parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organise, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:
    (a) begin at the earliest possible stage and are based on the multidisciplinary assessment of individual needs and strengths; and
    (b) support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.

United Nations Convention on the Rights of the Child: This Convention reaffirms the rights of all children to special care and protection. While all Articles contained in this agreement are relevant to all children, it is **Article 23** that holds a particular resonance for children with needs for neuro-rehabilitation. It states:

> *Children who have any kind of disability have the right to special care and support, as well as all the rights in the Convention, so that they can live full and independent lives*.

National legislative frameworks

Legislation governing disability in Ireland includes the following:

Equal Status Acts 2000 and 2004: These Acts promote equality of opportunity and prohibit discrimination in the provision of goods and services, accommodation and education across nine equality groups. The Acts confirm that discrimination in relation to access to and the provision of services on these grounds – including disability – is outlawed. Furthermore, the Acts allow for positive action to cater for the needs of disadvantaged groups or persons who may require services, facilities or assistance.

Disability Act 2005: The National Disability Strategy 2004 (Department of An Taoiseach, 2004) informs the development of services for people with disabilities by providing a framework of new supports built on a strong equality basis, placing the policy of mainstreaming of services on a legal footing. The Disability Act 2005 forms a key element of this strategy, by laying down legal requirements for public bodies as one mechanism of supporting equal participation in all areas of society by people with disabilities.

Employment Equality Acts 1998 and 2004: These Acts deal with discrimination within employment on any of nine grounds, including disability. Specifically, the Acts deal with issues including dismissal, equal pay, sexual harassment, working conditions, promotion and access to employment by virtue of any one of the nine grounds referred to within the Acts.

National Disability Authority Act 1999: This Act set up the National Disability Authority (NDA) as an independent statutory agency under the aegis of the Department of Justice, Equality and Law Reform. Among its functions, the NDA is tasked with assisting in the coordination and development of disability policy, undertaking research and developing statistical information for planning, delivery and monitoring of programmes and services for people with disabilities.

Citizen's Information Act 2007: This Act established personal advocacy services for people with disabilities and to support, promote and develop greater public awareness of social services and dissemination of such information by statutory and non-statutory bodies.

Building Control Act 1990: Part M of the Act provides for 'Access and Facilities for Disabled People', requiring that all new buildings for public use be accessible for disabled people. The Act was amended in 2000 to make houses 'visitable' by people with disabilities.

Education for Persons with Special Educational Needs Act 2004: This Act provides for the development of individual education plans for students with special educational needs. Under the Act, children with special educational needs will be educated 'in an inclusive environment with children who do not have special educational needs', unless this should not be in the best interest of the

child or would effect the educational provision for the other children. Although not yet fully implemented, this Act will ensure the provision of an 'Individual Educational Plan' for children with special needs. A child may be referred for an assessment which 'shall include an evaluation and statement of the nature and extent of the child's disability … and an evaluation and statement of the health and personal social services which the child will need so as to be able to participate in and benefit from education and generally to develop his or her potential'.

This Act, together with Part 2 of the Disability Act 2005, requires the health and education authorities to work collaboratively in ensuring that the health and education needs of children are identified, with the objective of meeting those needs.

National Social Policy

Two current policy documents locate disability within the social inclusion framework:

Towards 2016: The current national social partnership agreement – *Towards 2016: Ten-year Framework Social Partnership Agreement 2006-2015* (Department of An Taoiseach, 2006) – sets out an overarching framework within which key social challenges are addressed. A lifecycle approach is used around tackling poverty and social exclusion, as well as supporting improved systems of social protection. The Agreement contains commitments to modernisation and change across the health sector.

National Action Plan for Social Inclusion 2007-2016 (Office for Social Inclusion, 2007): Closely aligned to *Towards 2016* (*see above*), this Plan acknowledges that people with disabilities are at significantly greater risk of social exclusion and it endorses a vision – with associated agreed actions – where 'every person with a disability would be supported to enable them, as far as is possible, to lead full and independent lives, to participate in work and in society, and to maximise their potential'. Implementation of the National Disability Strategy 2004 is regarded as integral to attaining this vision.

Draft legislation on limited capacity: It is well acknowledged and established that certain cohorts, by virtue of functional limitations, require assistance in decision-making, particularly as it relates to their well-being. Currently, there is no legislative provision governing this. However, work is at an advanced stage in drafting legislation aimed at providing a legislative framework to support the decision-making of persons with limited capacity. This has the potential to impact on some persons with neurological conditions. Similarly, it will require system compliance so that the needs and rights of such people are established and respected.

National Health Policy

There are a number of key Government policies and strategies that guide the development of health services in Ireland, including:

The **National Health Strategy: Quality and Fairness 2001** (Department of Health and Children, 2001a) contains a number of overarching objectives geared towards provision of responsive, appropriate, quality care and support for all service users. Development of an action plan for rehabilitation is one key commitment identified in this strategy.

The **National Primary Care Strategy** (Department of Health and Children, 2001b) emphasizes the commitment of the health system towards ensuring a more equitable, accessible, appropriate and responsive range of quality basic health and personal services for all, located as close to the person's home as possible. The role of community involvement in planning and development of appropriate services is emphasized in this strategy.

The **National Strategy for Service User Involvement in the Irish Health Service 2008-2013** (Department of Health and Children, 2008a) confirms the commitment of the Department of Health and the HSE to provide opportunities for people who use health services, and their families and advocates, to have input into how services operate, to provide feedback and to be heard.

A Vision for Change (Department of Health and Children, 2006): This report by the Expert Group on Mental Health Policy identifies a comprehensive framework for the provision of accessible, community-based specialist services for people with mental illness, with the view of fostering positive mental health. It proposes service user involvement, multidisciplinary services taking a holistic view of mental health problems and promoting a recovery model. The report particularly identifies the need for a neuropsychiatry service: noting that one year after a traumatic brain injury, 20% of those diagnosed will have a diagnosable mental disorder and 40% will have behavioural problems, the report indicates that approximately 30-35 new referrals per 100,000 population per year could be expected for neuropsychiatry services. The report also identifies some inappropriate placements of people with frontal lobe injuries who demonstrate challenging behaviour. Relevant recommendations of the report include the development of neuropsychiatry teams linked with the two neuroscience centres in Ireland, together with establishment of associated 6-10 bed units.

In addition, there are a number of other Government publications that are relevant to the development and enhancement of neuro-rehabilitation services, including:

Irish National Audit of Stroke Care (INASC): Stroke is the third most common cause of death in Ireland and the most common cause of acquired major physical disability. The INASC Main Report by Horgan *et al* (2008) suggests that survivors of stroke may be left with avoidable and 'unduly prolonged' disability.

Deficits in current stroke care identified in the report include limitations in aspects of prevention, acute care and neuro-rehabilitation both in hospital and in the community. Recommendations are made on best practice management of stroke.

National Cardiovascular Health Policy 2010-2019: This policy, entitled *Changing Cardiovascular Health: National Cardiovascular Health Policy 2010-2019* and published in 2010 by the Department of Health and Children, recommends, among other things, that acute stroke care in hospitals should be carried out in dedicated stroke units to maximise capacity for sharing expertise and to ensure provision of a comprehensive service, with clustering of in-patient beds exclusively for this purpose and with care provided through specialised teams led by a consultant stroke physician. These teams would carry out neuro-rehabilitation planning, early interdisciplinary team assessment and neuro-rehabilitation as an integral part of stroke unit activity, as well as discharge planning and liaison with primary care service providers. The rehabilitation service for stroke would form part of an integrated neuro-rehabilitation provision in regional and local settings. It would encompass the needs of all those with needs arising from neurological illness or injury, regardless of age.

Older People: A sub-group of the 'Expert Advisory Group for Older People' in the HSE has produced a draft discussion document examining neuro-rehabilitation services for older people. The report concludes that there is a need for a policy for neuro-rehabilitation services for older people, based on a comprehensive needs assessment process. Currently, a strategy for older persons is in development and any policy proposals in relation to neuro-rehabilitation services for older people should take account of the recommendations contained in the present report since the Working Group on Neuro-Rehabilitation was tasked with developing a policy and strategy for all age cohorts.

PART 2:

PLANNING TOWARDS EFFECTIVE NEURO-REHABILITATION SERVICES

5. Needs analyses and mapping of neuro-rehabilitation service provision in Ireland

Needs analyses

Numbers needing neuro-rehabilitation services

The inadequacy of current information collection and application of data proves a major barrier in enabling quantification of the numbers of people needing neuro-rehabilitation in Ireland. Analysis of a range of data (from sources including the Census 2006, the National Physical and Sensory Disability Database, Irish and international literature, and various agencies) provides a rough estimate of 150,000 people needing these services on an ongoing basis.

The relative paucity of information is further compounded by even more limited information on the prevalence of less common neurological and neurosurgical conditions. Similarly, no concrete evidence appears available on the numbers of service users needing neuro-rehabilitation at different stages of the lifecycle or at different levels of care.

The limitations of data to inform a comprehensive needs analysis for this policy were recognised and additional measures were taken to strengthen and inform an evidence-based development of this policy. To this end, five of the more common neurological conditions were selected for detailed analysis, with a view to informing the types of neuro-rehabilitation services needed across a continuum of care. The conditions examined were acquired brain injury (other than stroke), cerebral palsy, multiple sclerosis, idiopathic Parkinson's disease and spinal cord injury. The service needs for people with limb absence were also considered in this process. Needs analysis included consideration of epidemiology of each condition, evidence for effective interventions and best practice in terms of cost-effectiveness.

The analyses were based on the following figures and estimates of neuro-rehabilitation service provision:

- In 2007, 3,271 people were recorded as having been discharged from hospitals in Ireland with a diagnosis of traumatic brain injury (TBI). However, based on an average hospital-admitting incidence rate of 235 per 100,000 population per year in the international literature (Tagliaferri *et al*, 2006), 9,964 people in Ireland annually would be expected to be admitted to hospital for injuries that included TBI.
- There has been no empirical study in Ireland, or in any other national population, of the prevalence of moderate or severe disability following TBI. However, prevalence *estimates* of moderate or severe disability after TBI from the USA are 1,893 per 100,000 population (approximately 2%) (Langlois *et al*, 2006) and from the UK (among working adults under 65)

are 1,200 per 100,000 population (1.2%) (Department of Health [UK], 2005b). Applying these figures to the Irish population (although the UK data exclude children and older people), the estimated prevalence of people in Ireland living with TBI-related moderate or severe disability may be between 50,878 and 80,260 – 1.2%-2% of the population.

- Reduced awareness of deficits following TBI is a well-established phenomenon linked to damage to the brain's frontal lobes. While physical difficulties are more accurately identified, the majority of people under-report cognitive, behavioural, emotional and social difficulties. The ensuing problems might be mitigated by follow-ups after hospital discharge. Evidence from other countries (Thornhill *et al*, 2000) suggests that post-TBI hospital follow-ups are inadequate and infrequent in spite of consequent disability This compounds the additional TBI burden imposed by reduced awareness.
- Stroke incidence in Ireland is estimated at about 10,000 new stroke events per year, with about 20% of people with stroke dying every year.
- Based on data from the National Cancer Registry of Ireland, the incidence of malignant brain tumour is about 296 cases per year. However, there are an unknown number of benign brain tumour cases each year, which may also cause acquired brain injury (ABI).
- About 5,500 people are living with the consequences of brain tumour.
- About 30,000 people in Ireland live with the consequences of stroke (Irish Heart Foundation Council on Stroke, 2001).

The total population prevalence estimates for the neurological conditions selected for detailed analysis are:

- **Cerebral palsy**: Approximately 2,120 in children; number of adults is unknown.
- **Idiopathic Parkinson's disease**: More than 7,000 people.
- **Multiple sclerosis**: Approximately 7,000 people.
- **Spinal cord injury**: Approximately 3,500 people.
- **Acquired brain injury**: Approximately 36,000 people (non-traumatic brain injury).
- **Limb absence**: Approximately 4,000 people, with about 500 new amputees needing prosthetic neuro-rehabilitation services each year.

Evidence for services

The needs assessment process confirmed that research evidence in relation to neuro-rehabilitation is fraught with challenges, particularly as randomised double-blinded controlled trials are neither feasible nor appropriate for the majority of interventions. Nevertheless, there is considerable evidence supporting early intensive coordinated neuro-rehabilitation, as well as many therapeutic interventions.

Neuro-rehabilitation services comprise:

- those therapeutic services aimed at preventing deterioration and at helping people regain and maximise function;
- those services that compensate for loss of function and the challenges posed by environmental and other barriers, so that the person can participate optimally in societal activities.

The WHO definition of neuro-rehabilitation ('*A problem-solving process in which the person who experiences a neurological impairment or loss of function acquires the knowledge, skills and supports needed for their optimal physical, psychological, social and economic function*') implies that the health and social gains being sought through this process are complex and interdependent. Achievement of durable outcomes may be challenging since maintenance of outcomes may be affected, both by progress in respect of the condition and by the quality of the continuum of care. Accurate measurement of outcome, using standard indicators, is naturally problematic here. Outcome measures that take the views of the service user into account may often be more appropriate for many elements of neuro-rehabilitation. Such indicators may include quality of life measures and levels of participation in activities. The views of families and carers are also important for measurement of neuro-rehabilitation outcomes and should offer an additional focus for monitoring.

Settings for services

The settings for service provision are determined by the complexity of the condition, by the number of people with the condition, by the competencies of care providers in the setting and by the phase of neuro-rehabilitation. It is acknowledged good practice that low-volume, highly complex conditions requiring much expertise in order to provide the necessary services might only be provided in one centre, whereas the expertise to provide services for people with high-volume conditions should be available in a greater range of settings. Since many people will have ongoing neuro-rehabilitation needs, they will need as many of these services as close to home as possible in order to maximise participation in all activities of daily living.

A person entering neuro-rehabilitation may access services through a number of different routes, depending primarily on age, type and severity of neurological illness or incident. The range and complexity of conditions requiring neuro-rehabilitation demand delivery of coordinated services along a seamless continuum of care. Typically, people requiring neuro-rehabilitation move along this continuum in both directions, depending on their health and care needs at different stages of the rehabilitative process. Services are provided at different levels, from specialised interventions to community-based care. People with neuro-rehabilitation needs should be treated in the right part of the continuum at the right time by staff with the necessary expertise required. The networks formed by intersecting settings and services at all levels of care should form a coherent system in which service pathways and processes are clearly mapped,

so that service users may be enabled to progress optimally through an integrated continuum of care and support.

The conditions that were explored in the needs analyses offered some indication of the volume of need for services. These findings were based on incidence and/or prevalence*, the complexity of the condition and the phases when more expertise might be required. Relevant findings pointing to a direction for planning around appropriate settings include:

- ABI, including stroke, is a high-prevalence condition with variable complexity, therefore services need to be available in many settings. Highly specialised services are needed to cater for specific wide-ranging sequelae, including those which are cognitive, emotional, sensory and physical, plus challenging behaviours and neuropsychiatric effects.
- A significant ABI will often require early intensive rehabilitation, commenced in the hospital of admission.
- Cerebral palsy is a moderate prevalence condition presenting in childhood with variable complexity. There may be high complexity in childhood as children's needs change rapidly during development.
- Idiopathic Parkinson's disease is a moderate-volume condition with variable complexity.
- Multiple sclerosis is moderately prevalent with variable complexity.
- Spinal cord injury has low incidence and high complexity in acute and post-acute phases. This means that treatment needs to be in a national specialist centre.
- Limb absence is a low-incidence, high-complexity condition, which requires specialised care and management, and may involve the use of prostheses or orthotics. Neuro-rehabilitation of people with limb absence is more than just providing prostheses and includes activities of daily living (ADL) training, cognitive training, mobility training, assistive technology, plastic surgery assessment, orthotics and splinting, orthopaedic assessment, prosthetic assessment and management, psychological assessment and psychotherapy. Specialised care is recommended internationally for people with limb absence.
- Children with acquired brain injury, spinal cord injury and limb absence will require ongoing intervention as they grow and develop, and the delayed effects of injuries, such as TBI, can manifest over the years.

Acquired brain injury (ABI) may lead to a mixture of physical, communicative, emotional and behavioural changes, with profound consequences for the individual and their family. Elderly people with head injury often have other pathologies that may have caused the injury and complicate subsequent medical treatment and neuro-rehabilitation. Cognitive, psychological and neuropsychological needs are central to those with ABI and there is a need for collaboration between social services and education/training.

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* Incidence is a useful measure for acute injury where intensive services are needed, particularly in the early phase, whereas prevalence is more useful for a progressive condition where intensive services are needed in bursts on an ongoing basis.

As mentioned in Chapter 4, the 2010 National Cardiovascular Health Policy (including stroke) considers the needs of people with stroke and it is likely that community-based and regional neuro-rehabilitation resources for neurological injury will need to reorient in such a way that stroke-specific expertise is retained, while the wider needs of all patients who require neuro-rehabilitation will be encompassed in all local and regional neuro-rehabilitation services.

Mapping of neuro-rehabilitation service provision in Ireland

A national mapping exercise was conducted for the development of this policy in order to provide a picture of current neuro-rehabilitation service provision throughout the country (*see Appendix 3*), together with associated existing service gaps and deficits. The numbers, range and diversity of neurological conditions, agencies, services and settings involved in neuro-rehabilitation meant that complete and accurate mapping of service provision was a particularly problematic task. Responses to the questionnaires sent to a wide network of service providers were varied; those responses received contained a breadth of content and detail, ranging from patchy and incomplete to very full and comprehensive. Again, this meant that formulation of an accurate picture of service provision, together with indications of numbers and designations of clinical team members, was fraught with difficulty. Nonetheless, an encouraging start has been made towards establishing a firmer idea of current neuro-rehabilitation service provision and ways in which these services are structured, accessed and delivered. This provides the basis for proposed detailed regional mapping of current service provision as a first step in the implementation of this policy.

Neuro-rehabilitation service provision may most usefully be described in terms of the different levels of service provision – from those available at a supraregional level offering specialised care on a national basis, to a range of services provided at community level.

Key issues and conclusions

The consultation exercise undertaken for the development of this policy demonstrates that there is a significant underdevelopment and fragmentation of neuro-rehabilitation services in Ireland. The mapping of existing service provision shows that specialist in-patient services are mostly concentrated at national level. It is welcomed that one of the medical specialists attached to the National Rehabilitation Hospital is currently working part-time in the HSE South Region with a view to setting up an appropriate structure to meet the holistic needs of those presenting for and requiring neuro-rehabilitation services. Regional hospitals have a variable availability of key rehabilitation staff, with a significant gap existing in the provision of neuropsychology. Key workers or case managers would ensure more coherent service delivery. Consultant-led neurology services

have benefited from efforts to develop services in the main regional hospitals and, in collaboration with consultants in older people's medicine, could provide the necessary clinical leadership for regional neuro-rehabilitation services, pending the appointment of medical rehabilitation specialists at regional level.

Services in the community are not inconsiderable, but are not delivered in a planned needs-based fashion. Many service users report a lack of services in the community. While this is true, it is also acknowledged that because of the significant fragmentation, it may well be that the structure of provision may also be a contributory factor. This can manifest itself in a number of ways, such as age-specific services, specific diagnosis or dual diagnosis, or behavioural presentations that challenge the response capability of services. Some services are delivered to defined sub-groups of the population that carry a specific diagnosis because the organisation providing them has been commissioned by the HSE to meet the needs of this specific group.

It is not possible with the data available to clearly map the precise levels of provision and relate them to the probable population-based need for services. This is an exercise that will need to be carried out during the early phase of the implementation of this policy. The number of delayed discharges awaiting referral to neuro-rehabilitation demonstrates a need to reconfigure these services. This will ensure that these people receive the care and support they need and will free up hospital beds 'blocked' by these people being inappropriately maintained in an acute hospital bed. There are also unidentified people in communities discharged from acute services who require neuro-rehabilitation but who have been unable to access it, either during their stay in the acute services or subsequently. In addition, there is anecdotal evidence that some people presenting at emergency departments with head injuries are not being assessed for neurological injuries. Subsequently, some of these people present at mental health services with mental health manifestations and are being treated accordingly. However, the underlying condition in many such cases is neurological and hence this cohort is not being identified and appropriately managed.

Similarly, the mapping exercise identified a number of services and service settings which, while responding to the neuro-rehabilitation needs of people, had access confined to certain age cohorts within the adult population. This is an issue that requires to be addressed in the service mapping and in reviewing and determining access criteria. Given the overall thrust of this policy, it is not sustainable or appropriate that access is determined by relevance to the adult life cycle.

6. Pointing the way to a national model of service delivery

Exploration of a range of issues relevant to neuro-rehabilitation, together with analysis of the outcomes of the needs assessment process, service mapping exercise and general consultation process, has made it possible to identify matters that are central to the promotion of improved neuro-rehabilitation service provision.

Priority issues may usefully be grouped thematically into the following broad areas:

- accessing services;
- service delivery;
- promoting health and social gain;
- factors underpinning planning and service delivery;
- measuring service effectiveness, efficiency and value for money.

Accessing services

The difficulties in accessing neuro-rehabilitation services were a recurring theme through consultations, submissions and questionnaires. Particular challenges were reported on accessing neuro-rehabilitation services at primary and community level, and in accessing specialist neuro-rehabilitation services once discharged from hospital. In some instances, it was impossible to access specific services due to a lack of trained staff within these services. The issues of long waiting lists and waiting times and the negative impacts of these have been well established. Many people may not be referred for rehabilitation in the first place due to lack of knowledge by potential referrers and the perceived delay in being accepted by rehab services. This is a particular challenge for the emergency units, where people present with head injuries but are not assessed for brain injury.

Barriers often appear most impenetrable when a service user has been discharged from the highly supportive hospital environment and is already contending with numerous physical, psychological and social challenges concerning re-integration into family and community life. The sudden perceived withdrawal of support at this particularly vulnerable phase risks the loss of those gains in health and well-being achieved while receiving neuro-rehabilitation services in the hospital setting. Many people lose rehabilitation gains when returning to the community because they may need to relearn their skills in the home environment and fail to do so without continued support.

Difficulties and delays reported in accessing services varied in different parts of the country, with obvious implications for one of the core principles that should

underpin provision – namely, equity. When people are in receipt of neuro-rehabilitation services and require additional support due to changing needs or to the effects of co-morbid conditions, appropriate service provision can be a considerable problem.

It is not only accessing neuro-rehabilitation services per se that poses difficulties. A range of communication, physical and some staff attitudinal barriers are also often perceived to exacerbate difficulties in accessing services appropriately. The inadequacy or absence of provision of clear consistent advice and information to support service users and assist them in navigating the health system are examples of such barriers. Similarly, the absence of clear consistent advice and information is a significant disempowerment of service users to develop the knowledge and understanding to enable participation in their own individual rehabilitative process and associated management.

For many, the absence of a key worker means they can 'drop out' of the system, particularly those with cognitive difficulties who will forget or be unable to plan and follow-up with appointments and programmes.

Service delivery

The service mapping exercise conducted for this policy (*see Chapter 5*) demonstrated the uneven and patchy nature of provision of neuro-rehabilitation services across the country, particularly in physiotherapy, speech/language therapy and neuropsychology numbers. This holds significant implications for equitable provision of these services. Neuro-rehabilitation services in Ireland are described as being considerably underdeveloped in comparison with other developed countries. Where gaps in services exist, it becomes even more crucial that existing service delivery is well coordinated, with available resources used to the optimal benefit of the population served in acute or community settings.

'Rigidity' and 'lack of flexibility' of service delivery were described in the submissions received. Rigid diagnostic criteria for entry into services, together with bureaucratic protocols and attitudes, were highlighted. People not falling into specific diagnostic categories or age groups were not accepted for treatment in some statutory and non-statutory services. The shift to a model where neuro-rehabilitation is *based on need rather than on diagnosis* implies an associated shift to a method of provision that reaches beyond some existing barriers to age- or disease-specific rehabilitation care, where staff working at primary and community level are equipped with the necessary competencies for management of all conditions and all ages presenting at this level. Clearly, this model would demand the formation of strong support and communication links between different levels of service provision.

Service users are negatively affected by uncoordinated, poorly integrated delivery of services. Elements such as unclear and inconsistent referral criteria, weakened

links between levels of service provision and poor discharge planning – all serve to undermine the positive impacts of neuro-rehabilitation. For service users who have multiple or complex needs, poor coordination and integration exacerbates challenges in meeting the aims of neuro-rehabilitation. Similarly, lack of integration of service planning and delivery hampers a comprehensive approach to the care and management needs of service users with a range of co-morbid conditions.

In order for rehabilitation to succeed and for personal outcomes to remain durable over time, there needs to be clear pathways of service delivery, clear referral criteria, admission criteria, individual rehabilitation programme planning with clear goal setting and outcome measures, and efficient discharge planning involving all stakeholders. Good communications are essential, including a comprehensive and integrative approach between all services, coordinated by an identified key person.

Transition from one level or phase of rehabilitation in a seamless process appears to be fraught with difficulty in many instances. This is particularly true for young people transitioning into adult services, for adults reaching 65 years of age and for those moving from in-patient care to the community. Periodic reviews should be built into the care pathway so that the needs of the person and their family can be reassessed and services reconfigured to better suit current needs. Key transition points, such as the move from paediatric to adult services, should be anticipated and planned for.

Promoting health and social gain

The valuable role played by health promotion – in preventing initial disability and subsequent deterioration in function, and in promoting maximum health and social gain once a person has sustained illness or injury – is well recognised and has been reiterated throughout consultations by service users and providers. The importance of incorporation of a health promotion approach into neuro-rehabilitation service delivery is further highlighted by the fact that many people with progressive neurological conditions are at a higher risk of heart disease and other lifestyle-related conditions.

Self-management is a critical phase in the rehabilitation journey for many people with neurological conditions and includes staying fit and healthy, and taking action to prevent illness and accident. Self-management has been shown to improve quality of life and to promote appropriate use of services. Primary care teams, in partnership with community rehabilitation teams, hospital, non-statutory and community services, have a key role in facilitating and promoting self-management programmes for individuals with chronic neurological conditions.

Provision of a variety of supports to enable optimal health and well-being, through working with a wide variety of agencies, is an integral component of a true

health promotion approach. Provision of appropriate accommodation, access to vocational support and availability of accessible public transport are examples of areas where positive early input can impact dramatically on quality of life. A 'whole system' approach to service provision demands that a high degree of collaboration exists across Government departments to ensure that the needs assessment processes are integrated to the greatest extent possible and that a range of necessary supports are in place at optimal times for service users. This latter point cannot be overstated since there are so many interdependencies across the whole system that, in turn, impact on the quality of response and on the quality of life of the person who requires such a response.

Service users with neuro-rehabilitation needs may require a variety of accommodation options over a period, depending on injury or condition, level of function restored, requirement for ongoing interventions, level of independence and so on. It is evident, therefore, that a range of community-based accommodation with varying levels of support is available for service users whose needs are best addressed within such supported living arrangements. At the same time, anticipatory proactive planning of necessary home adaptations and provision of complementary supports are critical to enable service users to return to their homes as soon as they are ready to do so. It is important that a coordinated intersectoral approach is employed towards the provision of such services.

Current constraints in relation to capital and revenue funding to progress ongoing development of a range of residential and respite settings is a significant challenge. However, this crystallises the importance of detailed mapping around current service provision in each HSE Region, together with the development of a coherent plan to maximise use of all available settings. It is equally important to support and empower people to maintain and maximise their function and the support routines they have developed in order to sustain their current level of function.

The provision of assistive technology as a means of supporting and attaining successful neuro-rehabilitation outcomes has already been emphasized in Chapter 3. Although significant monies are allocated in this area, there is scope for improved results. These technologies range from wheelchairs and communication aids and orthoses, to sophisticated SMART technology and tele-medicine.

Factors underpinning planning and service delivery

Human resources and organisational development

The area of neuro-rehabilitation is highly labour-intensive and requires a range of clinical, managerial, administrative and support skills. The ability to work in teams is a prerequisite for effective neuro-rehabilitation, while the challenge to continuously upgrade knowledge and skills is ever-present.

Any health worker working in neuro-rehabilitation should be attached to a rehabilitation team. Staff working in HSE services or in non-statutory agencies operate in increasingly pressured situations as growing demands for services compete against available resources. The challenges of delivering neuro-rehabilitation services in a fragmented system where numerous gaps exist in service provision are great. Engagement with staff in agreeing new ways of working towards integrated service provision is an essential first step. Redesign of neuro-rehabilitation demands a review of current arrangements, including staff numbers and locations, competencies, skill mix and priority needs for specific health disciplines, in line with the joint approach of the Department of Health and the HSE on integrated workforce planning. There is clear evidence that team-working, particularly using a transdisciplinary approach, provides better outcomes for both the person served and for the health system. A core objective of the HSE's (2007) Transformation Programme is to deliver care in the most appropriate way and in the most appropriate setting. Measures need to be taken towards more integrated delivery of services – these include development of common, shared assessment frameworks and protocols to facilitate service pathways, with clear guidelines around transfers and transitions.

It is important to recruit staff with the necessary skills and competencies needed to deliver high-quality service. Similarly, it must be stressed that in the future the system will be more reliant on staff developing and increasing their individual competencies rather than in increasing capacity through increased manpower. This, in turn, has significant implications for professional practice and boundaries, and for organisational boundaries.

Neuro-rehabilitation teams cannot function successfully without close links and associated referral pathways forged with other sectors of the HSE not directly involved in neuro-rehabilitation. Appropriate education and training of all healthcare providers is clearly necessary to inform an awareness of service users' needs and appropriate actions to be followed. The HSE document *Education and Development of Health and Social Care Professionals in the Health Services 2009-2014* is of particular relevance here (HSE, 2009b).

There is a clear imperative for strong focused leadership to drive the integration of current service provision across statutory and non-statutory sectors, to direct and support teamwork, to identify and promote good practice, and to foster all actions aimed at improving integrated service delivery. This leadership should be evident along the full continuum of care and supports. Obviously, leadership at national level is critical.

A crucial resource for neuro-rehabilitation are the many carers who deliver care and support services. Their contribution to the neuro-rehabilitation system underpins and sustains ongoing delivery and they are, in essence, core members of the team. The availability of carers is critical in enabling timely and successful discharge from specialist services to appropriate community settings. Effective carer input is a vital ingredient in the support network. Providing constant care and support can be a particularly onerous task, especially when

this is undertaken in somewhat isolated and unsupported settings. Any neuro-rehabilitation framework should therefore take due account of maximising the skills of carers as stakeholders. When the development and skills needs of staff are being considered, the needs of carers must be included. Similarly, there must be an acknowledgement that carers, like staff, can suffer 'burnout', hence the need to provide regular respite. At a time when there is significant pressure on healthcare staff to provide both additional and enhanced services, carers and family members, where possible and appropriate, should be upskilled by specialist staff to deliver some of the programmes under the guidance and management of the key professionals. There is evidence that such an approach is successful in other services, e.g. many parents deliver speech and language programmes to their children, which have been developed by a speech and language therapist who supports such provision through training, advice and oversight.

Supporting individual service users and carers to take optimal control of their neuro-rehabilitation programme is a core element of enabling progress towards attaining focused neuro-rehabilitation goals. Clear communication channels should be in place to ensure carers have access to advice and support.

Measuring service effectiveness, efficiency and value for money

Information is a critical tool to facilitate evidence-based planning and evaluation on all aspects of neuro-rehabilitation service delivery. The cycle of planning, implementing, monitoring and reviewing are accepted cornerstones in ensuring that services are appropriately planned, interventions are quality-driven and effective, and outcomes are maximised for the benefits of service users and their families, staff and the health system itself.

Information to support the planning of neuro-rehabilitation services

The HSE is a complex organisation and gathering information that is consistent, reliable, verifiable and robust is a challenge, particularly in the community sector where limited information and reporting systems exist. The difficulties in compiling comprehensive information on the needs for services, the nature and extent of available services and existing gaps in service provision are evident in this report. Collection and application of relevant data are priorities for allowing an evidence-based approach to the redesign, development and enhancement of the existing system of neuro-rehabilitation provision. Adoption of the International Classification of Functioning, Disability and Health (ICF) across the rehabilitation spectrum will facilitate information-sharing and make it possible to collect vital data in a consistent and internationally comparable manner. It will also ensure that the focus and ethos of the services are on the individual needs of the person served and their right to be supported to achieve this.

Quality of service provision

The HSE, working in partnership with a range of statutory and non-statutory organisations, has developed and approved a Quality and Risk Framework, which provides a structure for achieving excellence in clinical governance through implementation of an integrated quality and risk management system. Service plans, including those dealing with aspects of neuro-rehabilitation, are implicitly underpinned by this framework. Any development of a neuro-rehabilitation framework must therefore be consistently aligned with the principles of this framework.

The development of standards for application at all levels of care to ensure that services are delivered safely, appropriately and consistently is an intrinsic element of assuring quality neuro-rehabilitation service provision. Agreed standards should be consistent across all sectors and settings involved in delivering neuro-rehabilitation services. It will be crucial to incorporate any agreed protocols and standards into the renegotiation of service-level agreements with non-statutory agencies and service contracts with professionals, as part of an overall approach on the provision of integrated service delivery. Persons served and the delivery system need to have a clear understanding and confidence that the components of the services provided in the various settings are consistent with the protocols and specification as set out in the service arrangements. Similarly, there is an obligation on those providing services in those settings to ensure that their services are rehabilitation-proofed. This is going to be a significant challenge in the future, particularly in the development of the primary care teams and in the reorientation of a neuro-rehabilitation, rather than a condition-specific, delivery framework.

Active pursuance of good practice is a further pillar on which quality service provision should rest. This should be progressed through the twin actions of identifying and replicating identified good practice wherever possible, and promoting opportunities for learning and research in the area of neuro-rehabilitation. There is no doubt that significant models of good practice already exist throughout the country – the challenge remains to identify these and promote their replication or adaptation in line with the proposed new model of service delivery.

Measurement of outcomes

The need for improved measurement and reporting across the health system has long been recognised. Measurement of effectiveness and efficiency of interventions and associated health outcomes poses new challenges for the system. Measurement of outcomes must focus primarily on personal outcomes, but must also co-exist with clinical outcomes – including prevention of deterioration. However, other key elements must also be taken into account, such as resource utilisation, outcome of processes and the views of carers. Personal outcome measures need to be developed for the person served.

Cost implications and effectiveness

The Health Act 2004 charges the HSE to '*use the resources available to it in the most beneficial, effective and efficient manner to improve, promote and protect the health and welfare of the public*'. It is therefore incumbent on the HSE and the Department of Health to collaboratively explore best practice measures of ensuring quality services are delivered in as cost-effective a manner as possible. Planning and allocation of resources in accordance with identified need form a core part of this remit. This effort will ensure a focus on coordinating and reconfiguring existing resources in hospital and community settings, as well as eliminating duplication of provision and unsustainable practices.

Summary of comments from international experts

The Working Group, in considering how best to ensure that this report would achieve its task consistent with the terms of reference and that any recommendations were in line with best practice, decided that a draft report should be circulated for external validation to experts in the field of neuro-rehabilitation. The four experts who contributed to this process were:

- **Professor Alan Thompson**, Director, Institute of Neurology, University College London; Deputy Director, Comprehensive Biomedical Research Centre, University College London and University College London Hospital; and Garfield Weston Professor of Neurology and Neuro-Rehabilitation, Institute of Neurology, University College London.
- **Dr. Jurg Kesselring**, Head of the Department of Neurology, Rehabilitation Centre, Valens, Switzerland.
- **Professor Lyndsay McLellan**, National Consultant Advisor for the Priory Group's Neurological Rehabilitation Division; Medical Director at Unsted Park Hospital; and previously Europe Professor of Rehabilitation, University of Southampton.
- **Jacqui Lunday**, Director of the Allied Health Professionals, NHS Scotland.

Their comments and recommendations have been collected into general themes below (direct quotes are in *italics*).

Specialist and integrated services

Jurg Kesselring – *More general neuro-rehabilitation services are preferable (we practise them)*.

Lynsday McLellan – *There is no logical reason for providing neuro-rehabilitation services separately for stroke, ABI, MS, adults with CP, etc – the service categories should be determined more pragmatically not by medical diagnosis but by rehabilitation need.*

Alan Thompson – *A good general skill base can meet 75% of neuro-rehabilitation needs, but additional disease-specific expertise [is needed] within the team for the last 25%*.

The Model

Jurg Kesselring – *The metaphor of an optimal model of care is the chain – the most delicate is the organisation of the connections between the different stages and the communication between the people working in them*.

Alan Thompson – *The concept of mapping acute neurological rehab services on to the appropriate areas of acute clinical activity is sound – as long as there are not too many such centres … it is important to confirm location of acute services. The hub and spoke model makes good sense as long as resources are appropriate – spokes tend to get a bit squeezed*.

Huge challenge linking these acute centres to local primary care … proven very difficult … emphasize the need to include social care and the non-statutory sector in plans.

Consider tele-medicine as part of your hub and spoke model – we run very successful spasticity clinics at the National Centre.

Person-centred care

Lynsday McLellan – *The reason why neuro-rehabilitation services have to be person-centred is that need cannot be predicted simply by knowing the underlying diagnosis, nor even by making an inventory of all the impairments*.

Leadership

Lynsday McLellan – *Community services, especially your proposed geographically defined teams (an excellent concept, I think), should be supported by a designated consultant, but led by someone else. Clinical psychologists are excellent at this in relation to teams dealing with cognitive and behavioural impairments, but the main thing is to have a leader of any relevant neuro-rehabilitation profession who is experienced, likes working with other professions and has the self-confidence not to bias resources into their own discipline*.

Access

Jacqui Lunday – *State how access is to be improved – how services are to be redesigned or how capacity is to be built in*.

Gaps in service provision

Jacqui Lunday – *Emphasize the importance of tele-rehab, AHP consultant and assistant practitioner roles, non-statutory sector developments and carer support opportunities … Evidence for vocational rehab – there is an evidence-based review that gets scant attention … There are international innovative models, such as the WHO Community-based Rehabilitation*.

Alan Thompson – *Enhance numbers in allied professions*.

Equipment

Lynsday McLellan – *Issue of equipment, such as wheelchairs, communication aids and orthoses, as an integrated component of neuro-rehabilitation provision*.

Sensory disability

Lynsday McLellan – *Visual problems and hearing impairment to be mentioned*.

Outcome measures

Alan Thompson – *Encouraging to see plan to incorporate outcome measures, such as PROMs*.

Research and teaching

Jurg Kesselring – *Need to provide research and teaching opportunities*.

Funding

Lynsday McLellan – *A problem shared is a problem that someone else could solve without having to dip into one's precious resources! Somehow, you have to find a way of giving individual senior managers and individuals in funding agencies full responsibility for rehabilitation services across the board, but nothing else – so they are not distracted from their main responsibility and can then set about identifying (and justifying) their own priorities for development as determined by the characteristics of the population they serve and the environment they are in*.

Implementation

Lynsday McLellan – *Then let managers and teams use their resources to triage their referrals, deal with the priorities that are actually surfacing across the board in their patch, and report back to head office. I don't think any rehabilitation services (except the very specialised national ones) can be micro-managed from the centre*.

PART 3:

A FRAMEWORK FOR FUTURE SERVICE PROVISION

7. Proposed framework for neuro-rehabilitation service provision

The preceding chapters of this report have enabled an unfolding of issues, with some associated pointers of a broad direction towards ensuring enhanced service provision for people with neuro-rehabilitation needs. With this informed view, it is now possible to outline a more detailed framework for the progression of integrated neuro-rehabilitation services (*see Figure 1*). Thus, Part 3 of this report describes a proposed service framework for neuro-rehabilitation service provision that is (1) informed by the development of a clear vision, (2) underpinned by some core principles, as well as an analysis and articulation of the critical factors and considerations underpinning its implementation and associated actions to progress its development, (3) consistent with best practice and (4) more significantly, consistent with the Transformation Programme as developed within the HSE. The proposed service framework is intended to promote the following aspects.

Responsive services at appropriate levels

Neuro-rehabilitation is a continuum of services and supports that will require appropriate responses at local, regional and national level (depending on the complexity and intensity of the required response) and that will be determined and informed by clear referral and service protocols, developed nationally and implemented consistently throughout the delivery system. Individuals will receive appropriate neuro-rehabilitation services and supports based on assessed need from trained and competent staff in appropriate settings. These services and supports should maximise the natural supports that exist, or can be developed, in the home and in the community as required and throughout the lifecycle.

Managed neuro-rehabilitation networks

The establishment of managed networks for neuro-rehabilitation services in each of the 4 HSE Regions – each serving a population of approximately 1 million people – will facilitate the development of integrated quality neuro-rehabilitation services. It will also promote the primary aim of neuro-rehabilitation services, i.e. to support a person to optimise their ability to participate physically, psychologically, socially and economically. An appropriate management and governance arrangement will require to be put in place, one that, working with the national lead executive and clinician, will ensure that the framework proposed is consistently implemented throughout the country.

Service continuity

Service continuity will be enhanced by flexibility in service provision, allowing individuals to enter services at the point in the service continuum where their needs can most appropriately be met, thus enabling seamless movement between service levels and settings.

Support services

It is important to understand the essential nature of the wider range of support services that enable family and community inclusion and participation for people accessing neuro-rehabilitation services. It is also important to realise that such inclusion and participation are the primary goals and outcomes for service users. This wider range of support services includes housing, transport, educational and vocational services.

It is well documented that some of these supports will require to be accessed from non-health agencies, either separately or in collaboration with the health system. The structure for such provision needs to be developed and agreed, either through the development of referral protocols or the development of collaborative interagency processes where appropriate. Leadership on this issue will be provided at national level by the Office for Disability and Mental Health, which is within the Department of Health, and at local and regional level by the HSE.

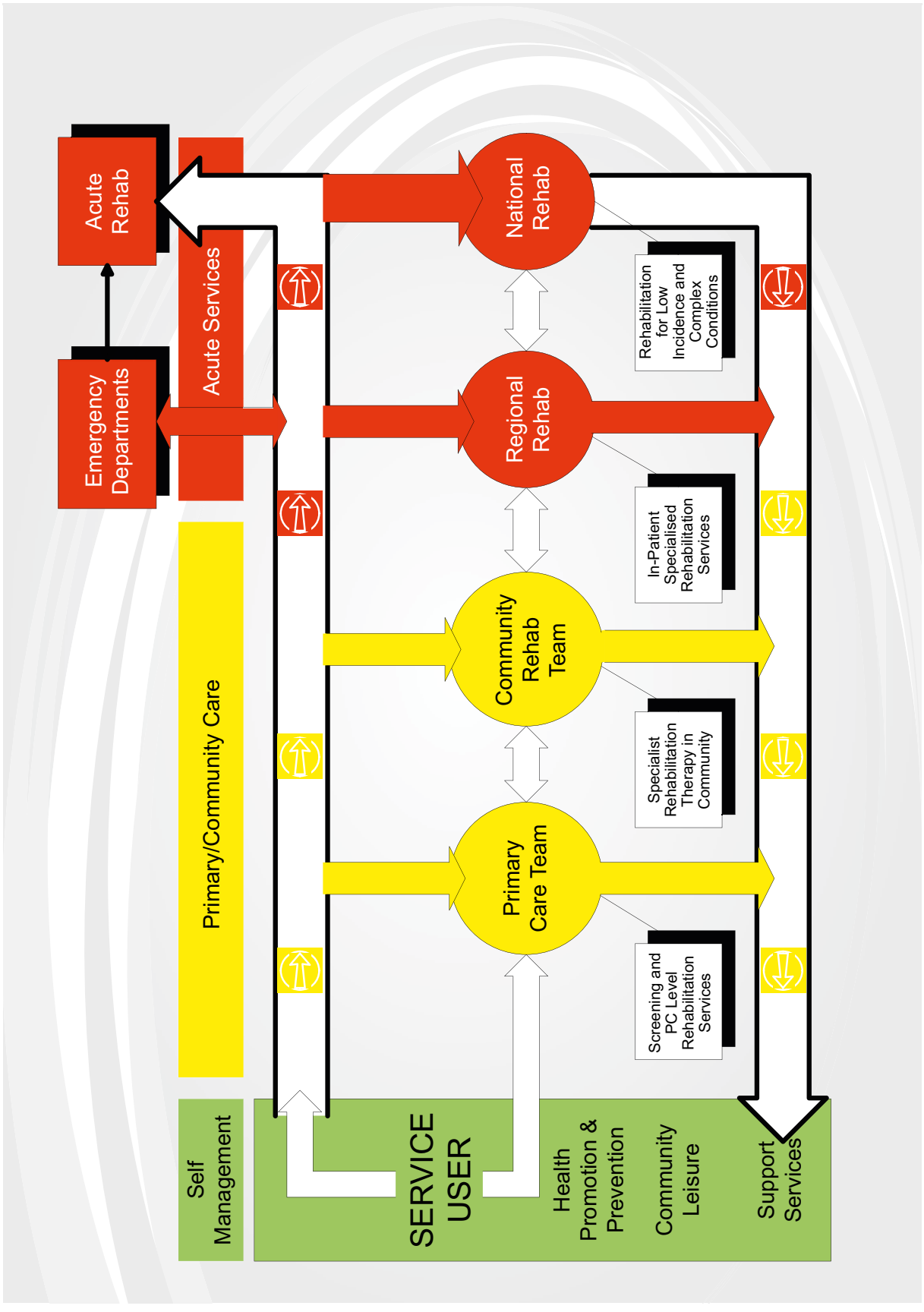
Quality services

Provision of quality care and supports will be informed by a clear focus on clinical governance and quality assurance. This will be achieved through a range of measures, including integrated teamwork, the development and sharing of agreed protocols, benchmarking against agreed standards, identification of good practice and support for evidence-based innovation, and clear measurement of efficiency, effectiveness and value for money.

Intersectoral commitment to neuro-rehabilitation

The person served has rights as a citizen to participate in the social and economic life of their family and community. The State, though its many utterances – in legislation, policies, strategies and developed practices – is committed to supporting the person served to overcome the barriers to participation by virtue of the disability. In this context, each arm of the State is required to support such participation by ensuring that where the required support comes within their remit, they fully and proactively contribute to enabling and facilitating this participation, and also to ensuring, to the greatest degree possible, maximum personal outcomes for the person served.

Figure 1: A future framework for neuro-rehabilitation service delivery



8. Key approaches underpinning the proposed neuro-rehabilitation service framework

While the remit of the Working Group was to develop a policy and strategy for neuro-rehabilitation, it is a strong view of the Working Group that there needs to be a well-developed neurology service that facilitates early diagnosis and treatment of neurological conditions. This, in turn, will have significant benefits to those presenting to neuro-rehabilitation services. Delays or failure to diagnose appropriately, with consequential inappropriate patient journeys, inevitably postpone access to appropriate rehabilitation and in some cases will reduce the likelihood of those people being referred to neuro-rehabilitation services.

The building blocks for a service framework that addresses neuro-rehabilitation needs effectively and appropriately at all levels of rehabilitation include the following elements, acting together:

- A strengthened approach to the incorporation of **health prevention and promotion strategies** in all aspects of service delivery.
- **Managed networks** within health service provision to enable excellence and consistency in service delivery and to support integration of service provision.
- A **community-based rehabilitation approach** to support inclusion and participation and to encompass a range of supports through health, vocational, educational and social services.
- **Clear linkages and pathways across service levels and settings**, including medical services such as neurology, psychiatry and palliative care.
- Increasing **use of research and technology** to support more efficient provision of neuro-rehabilitation services.
- The establishment of, or adoption of, an **agreed quality framework** to promote agreed standards, to develop service protocols and pathways, to monitor usage of managed resources, to audit systems and to meet accepted standards of clinical governance.
- To meet the holistic needs of persons consistent with their rehabilitation goals will require **intersectoral commitment**, either by collaborative working or development of referral protocols.

Strengthened approach to incorporation of health promotion and prevention strategies into neuro-rehabilitation service provision

Health promotion and preventative strategies have an important role to play in the primary prevention of some conditions requiring neuro-rehabilitation. The enduring nature of many of the complex conditions requiring neuro-rehabilitation creates significant challenges for those with the condition, their families and carers, and for health service provision. When these conditions are potentially preventable, every effort should be made to achieve the highest level of prevention.

All services have a responsibility for health promotion and prevention. Within the health system, primary care services are the first and ongoing points of contact for the majority of health service users, so a significant proportion of health promotion will reside at this level. Primary care services must be accessible to service users with disabilities. The local basis of primary care services must facilitate the delivery of national health promotion and preventative initiatives and campaigns (such as promoting the use of helmets and falls prevention) and though raising awareness in schools, workplaces, local community, leisure and primary care centres.

Primary prevention strategies include:

- High-quality antenatal, obstetrics and paediatric care – to reduce risk factors for cerebral palsy, including prematurity, very low birth weight and infection.
- Injury prevention in relation to road safety and occupational health – to reduce the risk of acquired brain injury and spinal cord injury. Obvious examples are cyclists wearing helmets and car drivers using seatbelts.
- Promotion of a healthy lifestyle, management of atrial fibrillation and hypertension – to reduce the risk of stroke.
- Preventing falls in the elderly.
- Early response to transient ischaemic attack. (TIA is a rapid, temporary loss of blood to a specific area of the brain that lasts less than 5 minutes, commonly known as a 'mini stroke'.)

Secondary prevention strategies include:

- Access to acute specialised neurological or neurosurgical care or advice when needed (e.g. stroke thrombolysis) to prevent irreversible brain injury or to neurosurgical consultation by tele-medicine on traumatic brain injury.
- Standards of care with the use of neuroleptics and other medications that are known to be associated with drug-induced Parkinsonism or that may make symptoms of idiopathic Parkinsonism worse.

Various Government strategies make recommendations on some of these areas, such as the current Road Safety Strategy, the HSE Falls Prevention Strategy and the National Cardiovascular Health Strategy. Recommendations in the World Health Report on Child Injury Prevention are also relevant here (WHO and UNICEF, 2008).

Managed networks

The concept of managed networks has already been mentioned in Chapter 7 as a key element in enhancing integrated working. The network approach provides an opportunity for integrated service delivery and promotion of partnership, sharing of resources and a common commitment to achieving the best outcomes for the service user across the varying levels and settings of service provision.

The development of neuro-rehabilitation networks will provide a framework to enhance integration and information-sharing across all neuro-rehabilitation

services, irrespective of the service provider. Clinical networks enable the planning, management and integration of services within a specific geographical region and for a defined cohort. All neuro-rehabilitation services are, to varying degrees, interdependent on each other. Effective integration of services is critical in order to achieve the best long-term neuro-rehabilitation outcomes for individuals and to ensure optimum use of resources. The purpose of the network is to deliver, in a managed way, a specific range of services to support the needs of patients or clients, and to ensure:

- mapping and mobilising existing neuro-rehabilitation resources in acute, post-acute and community settings in each HSE Region, to best meet the needs of all patients in the region with neurological conditions;
- coordination and integration of neuro-rehabilitation services across the network, to achieve best outcomes and ensure optimum use of resources;
- effective clinical and corporate governance;
- implementation of standards and comprehensive care pathways, with agreed protocols;
- regional planning of priorities for investment and development within strategic aims;
- opportunities for shared resources and joint working;
- regional centres will need to link to the national specialist centres and, in turn, to community providers through outreach, inreach, training, knowledge transfer and tele-links.

It is proposed that the neuro-rehabilitation network will be led by Clinical and Therapy Leaders, and include the National Rehabilitation Hospital (NRH) as the national hub, the regional acute hospitals as the regional hubs, the community-based teams, which will meet the needs of the patient groups who need neuro-rehabilitation care, and the primary care teams, which will play a role consistent with the expertise and workforce available to them. Staff at the national and regional hubs and on the specialist teams must have the necessary competencies to provide rehabilitation to people with neurological conditions. Staff at all levels will need access to training and rotation opportunities to grow and maintain the necessary expertise.

The regional hubs will have clinical leadership *and* consultant leadership (not necessarily the same) from a designated specialist in rehabilitation medicine, supporting existing neurologists and specialists in medicine for the elderly. As is intended in the HSE South Region, with the arrangement recently put in place, when it is possible to appoint specialists in rehabilitation medicine they play a key role in driving standards and quality of care across the network.

Individual users of neuro-rehabilitation services and their families or carers play a significant role in the neuro-rehabilitation process. Service providers will enable the active participation of service users, their families and carers in order to maximise use of the full range of knowledge and benefits that an inclusive approach will bring.

This requires:

- effective communication and the provision of information (in fully accessible and timely form) relating to specific conditions, the rehabilitation process, service provision within the network, and entitlements;
- professional staff to develop awareness of an individual's knowledge of his or her own condition and how it can best be managed;
- access to services when required, including continuing support services;
- the use of case management/key worker to facilitate a person-centred and a family-centred approach;
- appropriate supports for families and carers, which will enable optimum participation;
- particular attention is needed during transition phases, such as children moving to adult services or a move from hospital to community services;
- involvement of consumer panels or special interest groups in the planning and evaluation of service provision.

A community-based rehabilitation approach

Community-based rehabilitation is a strategy within general community development for the rehabilitation, equalisation of opportunities and social inclusion of all people with disabilities. It is implemented through the combined efforts of people who need the services, their families, organisations and communities, and the relevant governmental and non-governmental health, education, vocational, social and other services (WHO *et al*, 2004).

The outcomes of neuro-rehabilitation medicine and therapy services are intended to maximise a person's inclusion and participation in family, community, education, vocational and social settings in accordance with his or her choices, desires and interests. For a significant number of people, this requires additional services to support them in their daily living experience. Furthermore, without the additional service inputs, the gains due to therapeutic input risk being lost or having limited impact.

Supports for the provision of services – in residential settings, assisted living settings, respite facilities, educational services, vocational day services and other training centres – meet a variety of purposes for service users and are as significant in enhancing rehabilitation outcomes. Within a regional neuro-rehabilitation network, support services should be part of integrated service pathways, with clear roles and functions delineated and responsibility levels of each service provider outlined. Use of a community-based rehabilitation approach serves to focus all partners in service provision on achieving the best long-term outcomes for the person served.

Pathways to other settings

Clear links and pathways to other clinical, therapeutic and support services are essential for services users where their primary diagnosis is neurological in nature, but where other co-morbidities are present. Forging of links to mental health services is especially critical for management of service users who demonstrate a range of conditions or behaviours requiring professional intervention by mental health personnel. Partnership approaches should be adopted in line with the principles and recommendations contained in *A Vision for Change* (Department of Health and Children, 2006).

The need for palliative care services in non-cancer patients is emerging as an important issue. Palliative care services are a requirement for many people with neuro-rehabilitation needs at different times during the course of dealing with their condition.

Clear pathways and flexible arrangements allow sharing of expertise across domains to enable palliation and neuro-rehabilitation services to work together to provide for:

- people with rapidly progressing conditions;
- long-term neurological conditions, where the terminal stage of the condition is often unpredictable;
- pain management, nausea and breathing difficulties, in which expertise from palliative care professionals is often beneficial;
- palliative care services must be equipped to deal with people with complex presentations and diverse symptoms, such as cognitive, behavioural, physical or communication issues. Clear links to neuro-rehabilitation services will support this aspect.

The key worker plays a significant role in liaising between these services, the person and their family/carer.

Forging of links to enable ongoing research

Neuro-rehabilitation networks will include significant links to academic institutions and other clinically based research teams. These will support:

- evidence-based development at both local and international levels, ensuring that the neuro-rehabilitation service will be guided by best practice and not remain static in terms of rehabilitative development;
- education and development opportunities for the various disciplines involved in rehabilitation, including therapists, nurses and GPs. This will mirror network models being rolled out and may be achieved through structured placement opportunities in areas with a health science remit;
- placement opportunities for students in training to work as part of an expert interdisciplinary team;

- expansion of the neuro-rehabilitation service benefiting senior clinicians in terms of professional development and at the same time ensuring that graduates enter the workforce with an expertise in integrated neuro-rehabilitation service delivery.

This approach benefits practice in that it helps to ensure a focus on research and professional development, and with adequate supervisory methods, promotes service delivery based on best practice.

Technology

Assistive technologies provide solutions to many challenging aspects of neuro-rehabilitation care, including the complexity and long-term nature of need, geographical inequity and the labour intensity of neuro-rehabilitation services. The use of assistive technologies (e.g. communication devices, environmental control systems and personal computers) by service users can lead to increasing independence and greater involvement and re-integration into home, school or workplace, and community.

The demands for neuro-rehabilitation will be such that many services will have to be provided in the home or in local communities. Technology offers the opportunity of providing such services in the homes of many people with neuro-rehabilitation needs. For example, a current development in Ireland aims to provide home assessment and monitoring of cognitive training exercises using experimental technology. Computer-delivered cognitive training can enhance memory and other cognitive functions in elderly people, the benefits of which can translate into improved everyday function. New IT technologies are being developed to help measure and optimise cognitive, social and physical function in elderly people in the TRIL (Technology Research for Independent Living) Centre – a joint programme between Intel, TCD, UCD and NUI Galway (*see* www.trilcenter.org).

Tele-medicine is another technological development that provides the opportunity to create virtual teams that can educate, train and support local clinicians, with the additional benefit of increasing their skills in providing appropriate care. Only modest investment is required to develop tele-medicine facilities and improve clinical facilitation. This type of service allows users to carry out a programme of neuro-rehabilitation led by specialist expertise, but in the home, with monitoring and assessment of training to ensure maximum benefit. It would:

- reduce the need for hands-on therapy time and thus offer therapists the opportunity to help many more people;
- assist with monitoring improvement and thus build up an evidence base in cognitive training;
- be more sustainable as demography changes;
- be more flexible across conditions and needs, and thus could be used for many interventions where routine exercises are required.

Agreed quality framework

The establishment, or adoption, of an agreed quality framework enables:

- the development and maintenance of current field-driven standards, which improve the value and responsiveness of programmes and services delivered to the person served;
- ongoing self-evaluation and continuous systems improvement for service delivery;
- the development of an authoritative resource against which services can be benchmarked.

9. Range of service provision in the proposed neuro-rehabilitation service framework

The future model for neuro-rehabilitation service delivery shown in Figure 1 (*see Chapter 7*) offers a clear picture of a continuum of care, where service users access neuro-rehabilitation at primary, community, regional and national levels of care, depending on their particular needs at a point in time. It is evident that significant reconfiguration of existing services will be necessary as part of efforts towards realising this framework. Table 2 summarises the nature of services expected to be delivered at each level. Vocational goals are embedded in all rehabilitation at an early stage in all goal-setting and outcome-planning processes.

Table 2: Overview of neuro-rehabilitation services

PRIMARY **Care Teams**	• Generalist rehabilitation services to a defined population who are residing within the community. • A single service or multidisciplinary team approach. • Low to moderate intensity therapy.
GEOGRAPHICAL-BASED COMMUNITY **Neuro-rehabilitation Teams**	• Specialised neuro-rehabilitation services for individuals with neurological conditions who reside in the community. • Multidisciplinary team approach, goal-orientated therapy. • Moderate to high-intensity therapy.
REGIONAL **Neuro-rehabilitation Services**	• Specialist neuro-rehabilitation services. • Access through acute hospital services or direct admission. • High-intensity in-patient therapy and out-patient services.
NATIONAL **Neuro-rehabilitation Services**	• Specialist neuro-rehabilitation services for low incidence complex conditions, which are beyond the scope of regional services. • Caters for acquired brain injury (ABI) with complex psychological and behavioural needs; spinal cord injury; limb absence; complex stroke; and complex childhood neurological injury. • In-patient and out-patient basis. • High-intensity therapy. • Provides consultation outreach and inreach, training and tele-links to regional neuro-rehabilitation services.

Primary Care Services

- Primary care is the most appropriate level to meet most health and social care needs. Neuro-rehabilitation at this level is a vital component of the continuum of services to be configured as part of the neuro-rehabilitation networks and will require clear pathways and protocols.
- The development of team-based Primary Care Services and increased access to purpose-designed accommodation will significantly enhance the capacity for neuro-rehabilitation within primary care settings.
- Primary care teams will provide a generalist, low to moderate intensity neuro-rehabilitation service to a mixed population, including:
  - older people experiencing functional decline as a result of ageing;
  - people with musculo-skeletal conditions, such as arthritis;
  - those requiring neuro-rehabilitation following hospital discharge;
  - people with neurological conditions, such as stroke or multiple sclerosis.
- Primary care teams will only be able to provide the level of care that they have the appropriate staff and training to deliver. It is recognised that the development of primary care teams is not yet uniform across the country.
- The GP, as the first point of contact for medical services, plays a crucial role in linking a patient to the care pathways, but, in addition, the GP provides a role in preliminary diagnosis, managing general health and palliative care – and more specialist work if they have developed a special interest in neuro-rehabilitation. In this context, it is critical to the success of the integrated model of care that there exists within primary care, across the whole system, the required competency consistent with the referral and practice protocols that are developed for primary care. This issue will require to be addressed in undergraduate and post-graduate GP training and in the GP contractual arrangements with the HSE.
- The development of tele-medicine will enable the GP to access specialist consultation in an efficient, patient-friendly and cost-effective way.
- The limitations of primary care teams must be recognised – they have limited experience of neurological conditions, limited therapy staff and fewer patient numbers presenting – and thus they must be supported and linked to the wider network services to achieve the best treatment options in neuro-rehabilitation provision.
- Primary Care Services will be the coordination point for people with more than one condition. Many people present with neurological conditions and co-existing chronic conditions, such as diabetes or mental health issues. Equally, those with moderate and severe brain injury present in a complex fashion. Managing these presentations will require Primary Care Services to work in an integrated way across the neuro-rehabilitation network services and may require the appointment of a key worker or case manager.

KEY MESSAGES

- As Primary Care Services develop, neuro-rehabilitation should be an area of focus for primary care teams in dealing with agreed conditions and levels of intensity.
- Infrastructural development for primary care teams should have regard to the needs of neuro-rehabilitation provision.
- Key activity data and performance indicators are needed for neuro-rehabilitation services at primary care level.
- Clear pathways and protocols linking primary care teams to other network services are essential.
- GPs have a central role to play in the continuum of care and in conjunction with other primary care team members in setting goals and planning outcomes. This will require a review of current GP training schemes and contractual arrangements.

Community-based Neuro-rehabilitation Teams

- Community neuro-rehabilitation teams (CRTs) will be developed from existing community-based therapy staff to provide moderate and high-intensity neuro-rehabilitation inputs and to enable activity and participation in community settings across home, educational, work and social environments. The CRTs will provide specialised neuro-rehabilitation therapy services in association with a cluster of primary care teams within a specific geographical region for a defined population. Through a mapping exercise, each region will determine what are the precise resources available to the area and work with the different service providers to ensure that these resources are reconfigured in teams that retain specialist and disease-specific expertise, but also broaden their collective remit to meet the needs of all those with neuro-rehabilitation needs. This reconfiguration will be directed by the regional lead on neuro-rehabilitation.
- CRTs require a degree of specialisation and training that will enable them to provide services to people with complex presentations, such as:
  - those who require a degree of specialised input beyond that available from a primary care team;
  - those who require a level of intensity of therapeutic input that is not possible from a primary care team;
  - those who do not require in-patient facilities, but do require high-intensity neuro-rehabilitation inputs;
  - those who need to transition from hospital to home.
- CRTs will form a critical link in the care pathway by:
  - facilitating early discharge and continuity of therapy from acute and regional in-patient neuro-rehabilitation facilities;
  - assessing and making recommendations on vocational options such as returning to work, educational and occupational activities;

  - developing local area networks comprised of both mainstream agencies (e.g. FÁS, Supported Employment Services, HSE and HSE-funded agencies) and job facilitators in the Department of Social Protection in order to coordinate service delivery and service pathways, as well as coordinate vocational rehabilitation service delivery;
  - supporting primary care teams through advice, consultation and shared care approaches to assessment and intervention.
- CRTs will typically comprise the disciplines of occupational therapy, physiotherapy, speech and language therapy, psychology or neuropsychology, and social work. Staff will retain disease-specific management expertise while ensuring they deliver care to all those with neuro-rehabilitation needs. They will ensure strong links with regional hospitals and national levels of expertise and support, and will, in turn, support ongoing care provision through emerging primary care teams.
- Community-based rehabilitation will support the concept of self-management.

Regional and Acute Hospital Services

- A single managed network for neuro-rehabilitation services will span each of the 4 HSE Regions, covering a population of approximately 1 million people. The network will facilitate consistent adherence to national standards, protocols and defined care pathways.
- Efforts will be progressed towards the development or enhancement of appropriate in-patient facilities, with dedicated, trained neuro-rehabilitation staff in designated areas of existing facilities. New facilities with dedicated neuro-rehabilitation capacity may develop in the future depending on existing infrastructure. Facilities will provide specialised and high-intensity neuro-rehabilitation services to:
  - people with progressive neurological conditions;
  - people with acquired brain injury;
  - adults with non-progressive disability conditions;
  - all adults with neuro-rehabilitation needs who would benefit from the service;
  - stroke patients.
- Out-patient services may be based at regional units in order to maximise the availability of clinical expertise and associated facilities.
- Regional in-patient services will require to be guided by consultant neurologists and geriatricians pending the appointment of consultants in rehabilitation medicine (as has occurred in the HSE South Region), who will then provide clinical leadership. Leadership should also emerge from therapy leads and in some cases psychology services when the primary issues are cognitive and emotional.
- Paediatric care will be based around existing paediatric units and will be defined after the regional mapping exercise has been completed. These will link very closely with the national providers.

- Defined protocols for access to regional in-patient facilities will be in place to ensure equitable service provision to the range of potential service users.
- Neuro-rehabilitation should begin the first day after onset of a physical or sensory impairment. Acute neuro-rehabilitation management focuses on reducing impairment and preventing complications secondary to the conditions, until the patient is discharged or transferred to post-acute or community neuro-rehabilitation services, as determined by need. Timely transfer to other neuro-rehabilitation services is imperative to ensure that a patient's needs are managed effectively and that acute hospital beds are efficiently optimised. Key workers or case managers should be identified to coordinate the patient's progress through the care pathway.
- Early supported discharge from acute services is a positive outcome when patients with neuro-rehabilitation needs can be cared for by resourced community neuro-rehabilitation teams and primary care teams, both of which can provide the appropriate intensity of neuro-rehabilitation care required.

KEY MESSAGES

- A managed network corresponding to each of the 4 HSE Regions will provide the framework for services at regional, community and primary care levels.
- Regional services will include in-patient neuro-rehabilitation beds, with specifically trained staff.
- In-patient facilities will be closely linked to community-based neuro-rehabilitation teams, acute hospital services and the national (tertiary) service.

National (Tertiary) Neuro-rehabilitation Service

- The national specialist neuro-rehabilitation service, based at the National Rehabilitation Hospital, is, by necessity, a high-cost, low-volume service provided for people with uncommon or highly complex conditions, who typically need high-intensity interventions from skilled specialised staff over a period. It will be essential that the emerging approach to enhancing neuro-rehabilitation care is built on consistent approaches to creating mechanisms to resource the regional and community levels of provision from the national specialist centres. The National Rehabilitation Hospital will need to develop clear ways to pass on or 'cascade' their expertise through the regional neuro-rehabilitation networks, possibly through individuals taking on specific responsibility for specific networks.
- This tertiary-level service provides a level of care for patients whose needs cannot readily be met at regional level. Those with low-incidence conditions who require intensive specialised neuro-rehabilitation inputs that are beyond the scope of regional services will access the national (tertiary) service. This may include people with spinal cord injury, those with limb absence and those with complex cognitive or behavioural difficulties associated with brain injury.

- Staff at the National Specialist Centre do, and will, have specialist training and expertise in neuro-rehabilitation. Clinical staff should include doctors trained and accredited as specialists in rehabilitation, skilled nursing staff and allied health professionals in clinical specialist posts, together providing an interdisciplinary service to patients.
- The National Specialist Centre does, and should, have the range of sophisticated equipment and physical facilities necessary for neuro-rehabilitation at this specialised level.
- The National Specialist Centre must maximise its contribution to neuro-rehabilitation through the provision of outreach clinics and structured arrangements for rotation of staff from other rehabilitation centres, so as to acquire particular expertise as well as participation in training, tele-medicine and other supports to both regional and local providers.
- Outreach, advice, consultation and training for regional specialist staff is a vital component of the national (tertiary) service.
- In light of the enhanced coordination of regional services, the capacity of the national (tertiary) neuro-rehabilitation service should be reviewed to ensure that the requirements of the population are met, not only in respect of available places but also for adequacy of services equipped to deal with highly complex presenting conditions.

Neuro-rehabilitation services for children

The approach to neuro-rehabilitation services for children is quite distinct to that needed for adults. Emphasis in neuro-rehabilitation for children – where growth and development are key factors – is placed on maximising function with reference to developmental milestones. Staff involved with children's neuro-rehabilitation services require a distinct set of skills and competencies. Timely access to appropriate rehabilitation is vital for children with identified needs.

Due to medical and technical advances, children who in the past would not have survived are now surviving into adulthood. A key feature of current paediatric neuro-rehabilitation provision is that on reaching adulthood, some clients have remained with the paediatric neuro-rehabilitation services because the required competencies and capacities do not reside with adult services. Accordingly, clear protocols need to be developed to enable transitioning from paediatric to adult services.

Neuro-rehabilitation services for children focus on dealing with:

- children with delayed conditions (congenital) who require input to reach developmental milestones and goals;
- children with progressive conditions who require input in minimising loss of function;
- children with traumatic injury who require input in maximising gain and restoration of function.

Paediatric neuro-rehabilitation needs to be served by the same hub and spoke/ networked model of care as identified for adults (*see Chapter 7, Figure 1*). Accurate mapping of current services and need should inform capacity and future integrated service provision. Services for children should be delivered within a family-centred ethos. This will require an integrated, multidisciplinary, multiagency approach with a range of service providers. Positive liaison between health and education services is critical in this regard.

The Working Group tasked with the development of this policy gave significant time to considering how best to develop the framework for children's services, consistent with the unique needs of children and the obligations to them as provided for in legislation. It was concluded that the best interests of children with neurological presentations and associated rehabilitation needs are served by including children with neuro-developmental delay within a children's framework. The Working Group is aware of current work being done in this area through the review and reconfiguration of paediatric services and has concluded that the needs of this cohort of children should be included in that project. However, the vision and underpinning principles of this neuro-rehabilitation policy and strategy (*see Chapter 3*) need to be reflected within that framework.

10. Assuring quality

The need to develop a framework to ensure quality assurance in provision of neuro-rehabilitation services has been a recurring theme throughout this report. The establishment of a quality framework that promotes and supports clinical and corporate quality is an urgent priority for neuro-rehabilitation services. Collaborative efforts with the Health Information and Quality Authority (HIQA) are necessary to ensure progress in this area, while the newly established HSE Clinical Directorate will play a key role in progressing actions on quality, risk and governance.

Leadership, accountability, management and reporting structures of networks or groups of services should be in accordance with the recommendations made in the Report of the Commission on Patient Safety and Quality Assurance, *Building a Culture of Patient Safety* (Department of Health and Children, 2008b), and should provide for the planning, management and integration of services with a specific geographical region and for a defined cohort.

Clinical effectiveness

To ensure that people achieve the best outcomes from neuro-rehabilitation services, it is essential that healthcare professionals have access to the most up-to-date information. Neuro-rehabilitation programmes must be guided by evidence-based practice relating to the particular condition or specialty area.

Neuro-rehabilitation services should be goal-orientated, transparent, measured and outcome-focused. They should adopt a continuous improvement approach to service provision. All health professionals working in neuro-rehabilitation services should be engaged in clinical audit. Care pathways and national clinical guidelines for the major neurological conditions need to be developed and implemented locally in all neuro-rehabilitation networks. Neuro-rehabilitation is a complex process with short-term, intermediate and long-term goals. All neuro-rehabilitation intervention should be focused on the achievement of long-term durable outcomes that will provide the desired level of participation for the person served. In a service environment, organisational success cannot be achieved or sustained without success for the person served. Actively engaging the person served as part of the planning and service processes has been demonstrated to result in better outcomes. The important role of input from such people and from other stakeholders must be recognised as a requirement of any quality framework and, in turn, this will contribute to and promote long-term organisational and clinical excellence.

Research in neuro-rehabilitation should be planned, needs-based and outcome-focused. It should support the development of a quality framework and national standards. Research should be focused on the impact of rehabilitation on community engagement, life participation and outcome measures based on quality of life, as well

as focusing on outcomes at an impairment level. Furthermore, the research agenda must include methodologies that incorporate the perspective of the service user.

Staff learning, training and development

The quality of neuro-rehabilitation services is dependent on the knowledge and competence of people delivering these services. People who have neurological conditions should be treated at all stages of their neuro-rehabilitation journey by health professionals who have the skills, knowledge and experience in delivering neuro-rehabilitation services, including specific competencies to manage neurological conditions.

The clinical competencies of all individuals working in neuro-rehabilitation services should be commensurate with the level of specialism required. The development of this specialism is dependent on access to appropriate training, education and experts in the field of practice. Neuro-rehabilitation networks should facilitate the rotation of health professionals across the neuro-rehabilitation spectrum. A system of life-long learning and professional development for health professionals working in neuro-rehabilitation is required, with regular competence assurance.

Staffing levels and integrated workforce planning

Requirements for staffing ratios will vary across services depending on people's needs and the intensity and complexity of services being delivered. An appropriate skills mix is essential to ensure best outcomes. Staffing ratios and competencies should be a component of a neuro-rehabilitation services accreditation process (*see below*).

Accreditation of services

Accreditation of services is a positive driver ensuring provision of high-quality services according to internationally accepted norms. The Commission on Accreditation of Rehabilitation Facilities (CARF) is a relevant instrument in this regard. It is proposed that engagement be initiated with the HIQA towards development of a national approach to accreditation of neuro-rehabilitation services.

Key actions on quality assurance

Actions to progress quality assurance may include the following:

- The existing quality framework for rehabilitation services should be adopted and adapted, involving key stakeholders.
- Each neuro-rehabilitation network must have robust clinical and corporate governance structures.

- A knowledge management system for healthcare and social services (managed knowledge network) should be developed, which will facilitate effective access to knowledge and an evidence base for rehabilitation, together with the sharing and generation of new knowledge.
- National standards, clinical guidelines and care pathways for the major neurological conditions need to be developed.
- Neuro-rehabilitation services should be outcome-focused, with particular emphasis on activity and participation.
- People who have neurological conditions should be treated at all stages of their rehabilitation journey by staff who have the appropriate skills, knowledge and experience, consistent with the requirements from the particular setting in which they operate, to deliver neuro-rehabilitation services.
- The International Classification of Functioning, Health and Disability (ICF), already adopted by Government, should be reflected within neuro-rehabilitation services.
- Comprehensive information management systems need to be developed that capture all elements of service provision and support the measurement of outcomes and their durability.
- People accessing neuro-rehabilitation services should have a written rehabilitation plan (with their own copy), detailing:
  - current needs;
  - key contacts;
  - responsible services/professionals;
  - sources of continued information, support and advice.
- Families and carers need to understand the neurological condition of their family member and receive guidance on how to interact appropriately with the person, how to access services, how to act consistently with professional rehabilitation services, and how to continue with home-based rehabilitation. Written information must include:
  - symptoms and signs, and what to do about them, which may include the need for further investigation;
  - reassurance about symptoms and signs that are not unexpected;
  - advice about safety and self-care measures;
  - details of community resources;
  - information for carers on the difficulties of a condition that cannot be detected by people who do not have clinical training.
- Families and carers crucially require support to sustain their efforts in caring for loved ones. They may also need family therapy or counselling since caring for a family member who may have been dramatically changed by their brain injury, for example, can have a major impact on other family members.
- Staffing levels and skills sets should be researched for different levels of service provision and various settings.
- The healthcare and social services must deliver quality-assured neuro-rehabilitation services that are achieving the best possible outcomes for people. To do this effectively, evidence-based markers of good practice for rehabilitation services need to be developed.

11. Ensuring implementation

This report provides a framework facilitating a strategic coordinated approach to effective neuro-rehabilitation service delivery. However, development of this framework is only a first phase in the development of a neuro-rehabilitation service where all service users may avail of excellent treatment, care and management, provided in ways that promote and maintain optimal function and independence.

Implementation of this strategy will not be achieved unless there is proactive leadership at corporate and clinical level, which will have the capacity to mobilise existing resources consistent with the identified framework and which will ensure that the various required competencies and skills are identified and developed.

Realising the actions recommended in this policy and strategy may be expected to provide real challenges, especially against a landscape of significant economic and resource constraints. A 3-year implementation plan will address those key actions that can be initiated and implemented within a short timeframe and on a cost-neutral basis, while working towards the achievement of the longer term vision outlined in Chapter 3. Thus, the focus for service development in the first 3 years of this policy and strategy must be on:

- network development;
- integration of services;
- development of protocols that will have mandatory compliance across the delivery system;
- reconfiguration of existing resources;
- achieving greater cost-effectiveness through the development of greater competencies by those tasked with delivering services;
- increased teamwork and using interdisciplinary approaches;
- more interagency collaborative working.

Many references have been made throughout this report to the need for an intersectoral approach and commitment if the full continuum of need is to be addressed. The development of joint-working or interagency protocols are a key requirement and need to be central to any implementation plan.

KEY ACTIONS

1. Principles to guide neuro-rehabilitation service development

Rehabilitation services will be provided to ensure equity of access, social inclusion and empowerment of service users.

1.1 Rehabilitation services will strive to provide high-quality, reliable, person-centred care, delivered as close to the home as possible.

1.2 Systems will be adapted to the individual, with service provision adapted accordingly.
1.3 Service users and carers will be central to the design and delivery of care plans.
1.4 A commitment by all State agencies to meeting their obligations to people with neurological conditions who require a holistic response to enable them to meet their assessed needs.

2. Implementation structure

Services will be developed within the HSE Clinical Directorate structure to ensure appropriate planning, service delivery and governance for neuro-rehabilitation services.

2.1 A National Clinical Lead with designated responsibility for and experience in neuro-rehabilitation will be appointed, together with the assignment of an Executive Lead to drive the reconfiguration of service provision to better meet the needs of all those who need neuro-rehabilitation services. They, in turn, will need to work with the support of a National Therapies Lead from the area of neuro-rehabilitation and consult with service users.
2.2 The National Clinical Lead will work with 4 regional implementation teams, made up of executive leads, clinical leaders in rehabilitation medicine (drawn from the medical rehabilitation specialist area) and therapy leaders, with public health specialist input. They will engage service users directly to ensure implementation is needs-led.
2.3 The primary task of each regional implementation team will be to carry out a detailed mapping of the existing acute and community resources (both statutory and non-statutory) available in its region and also those resources required to meet neuro-rehabilitation needs. It will identify any duplication of resources and efficiencies achievable. This will include staffing and physical infrastructure, both in-patient and ambulatory. It will incorporate what is learnt from the forthcoming review of day services, which is nearing completion. Short, medium and long-term service quality improvement plans will be developed within the national framework for neuro-rehabilitation services.
2.4 The mapping exercise in the North East and North West will consider whether developing links with neuro-rehabilitation services in Northern Ireland would benefit those living near the border.
2.5 A clear plan will be developed for upskilling regional and community services through sharing national expertise in training initiatives, staff rotation, outreach and inreach, and tele-links between national specialist experts and the rest of the network. Specialist expertise in non-statutory service delivery will contribute to training and upskilling regional and community-based service providers.
2.6 Planning must take account of the need to support carers in their central role in neuro-rehabilitation and care.

3. Methodology for implementation

A Framework of Services will provide the appropriate continuum of national, regional and local services needed at the various stages in the pathway of the person served.

3.1 Clear care pathways will be established, starting with the prevention of neurological injury, which ensure clear linkages across service levels and settings, particularly between national, regional and local service provision.

National

3.1.1 The current provision of services in the National Rehabilitation Hospital will be reviewed with the hospital to identify ways of managing the needs presenting to the hospital in the most efficient way. This will include identifying opportunities to bring the care of some patients at different stages of their rehabilitation closer to their home and will review the adequacy of the capacity of the national service to meet the population need following the development of the 4 regional networks (*see Action 2.2 above*).

3.1.2 Best practice guidelines for care should be developed or adapted from existing models. Service standards, guidelines and pathways should be overseen by the Office of the Director of Clinical Care and Quality.

Regional

3.1.3 The 4 HSE Regions should ensure that clear links are developed with neurology, mental health and older age medicine services, and promote integration of acute, specialist and primary care services directed at people with neuro-rehabilitation needs.

3.1.4 Arising out of the regional mapping exercise (*see Action 2.3 above*), regional non-age-limited in-patient neuro-rehabilitation services should be identified to provide intensive rehabilitation inputs.

3.1.5 A Communication Plan should be developed to ensure that all stakeholders are kept informed of progress being made on implementation. Planning will involve staff engaged in neuro-rehabilitation service delivery in statutory and non-statutory organisations.

3.1.6 A review of the current role and function of those, professionally and organisationally, who are involved in neuro-rehabilitation provision will require to be carried out, so as to ensure that there is equitable capacity to meet the continuum of need at the level required. This will have implications for organisations which historically have been associated with and dedicated to condition-specific services. It may mean that some elements of services that were historically attached to specific agencies may now require to be provided through alternative arrangements.

Primary and Community

3.1.7 Community neuro-rehabilitation teams should be developed from resources identified in the mapping exercise, enabling discharge from in-patient facilities and with the primary care teams preventing unnecessary re-admission. Key worker roles should be developed in these teams. All staff should receive training in (i) SMART goals setting; (ii) compiling neuro-rehabilitation care plans adopting a team approach; and (iii) discharge planning and managing the transition between services.

3.1.8 Primary care level neuro-rehabilitation services should be enhanced through links to community-based and regional provision. This will involve training for therapy staff on primary care teams in the care of particular patients cared for by the regional and community services.

3.2 Training and education will be central to the early enhancement of existing professional resources for neuro-rehabilitation. Rotational programmes for therapists will be established to facilitate shadowing, joint working across national, regional and community rehabilitation teams and Primary Care Services. Training opportunities in rehabilitation medicine should be included in higher specialist training for neurology, older age medicine and general practice training.

4. Information for neuro-rehabilitation

Development of appropriate information and communication systems will support neuro-rehabilitation service delivery systems.

4.1 Good information provision is a vital component of neuro-rehabilitation services. The development of agreed appropriate performance indicators for use in the National Service Planning process should be progressed by the National Clinical and Executive Leads in the HSE in collaboration with the Department of Health.

4.2 Strong links to academic institutions should be established or maintained in order to promote research in the field of neuro-rehabilitation.

5. Children's neuro-rehabilitation

Enhancement of neuro-rehabilitation services for children should be supported by the national model of care for children's services.

5.1 The National Clinical Lead will draw on expertise in the paediatric care area for this role. They will work with the Development Board of the new National Paediatric Hospital to ensure the development of national neuro-rehabilitation care there. This will require planning for the transfer of services from the National Rehabilitation Hospital upon completion of the paediatric hospital.

5.2 Attention will be directed at the period when children transition from child to adult services.

5.3 This work will link to the recently established Dublin Paediatric Hospitals Group.

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Appendix 1: Members of Neuro-Rehabilitation Steering Group, Working Group and Sub-Groups

Note: Roles ascribed are as existed at the time of the establishment of the Working Group and Sub-groups.

STEERING GROUP membership

Dr. Philip Crowley, *Chairperson*	Deputy Chief Medical Officer, Department of Health and Children
Ms. Bairbre Nic Aongusa	Director of the Office for Disability and Mental Health, Department of Health and Children
Ms. Anne Doherty	National Director, National Hospitals Office, HSE
Ms. Laverne McGuinness	National Director, Primary, Continuing and Community Care, HSE
Dr. Pat Doorley	National Director of Population Health, HSE

WORKING GROUP membership

Mr James O'Grady, *Chairperson*	Disability Policy Advisor to Department of Health and Children
Dr. Philip Crowley	Deputy Chief Medical Officer, Department of Health and Children
Mr. Dermot Ryan (until Sept. 2009)	Office for Disability and Mental Health, Department of Health and Children
Ms. Fionnula Duffy	National Hospitals Office, HSE
Ms. Marion Meany	Lead Local Health Manager, Dublin Mid-Leinster, HSE
Dr. Tim Jackson	Public Health Specialist, HSE South
Ms. Patricia McLarty	Disability Specialist, HSE
Ms. Charlotte McCoubrey	Department of Health and Children
Dr. Aine Carroll	Clinical Director, National Rehabilitation Hospital
Dr. Hugh Monaghan	Consultant in Neuro-Rehabilitation, National Rehabilitation Hospital
Mr. Michael Clavin	Consumer Representative, BRÍ
Ms. Barbara O'Connell	Chief Executive Officer, Acquired Brain Injury Ireland (formerly Peter Bradley Foundation)
Ms. Edel Callanan	Physiotherapist, HSE West
Ms. Elaine Whelan	Speech and Language Therapist, HSE West
Ms. Alma Joyce	Occupational Therapist, HSE Dublin
Dr. Salvatore Giangrasso	Neuropsychologist, Headway
Ms. Anne O'Loughlin	Principal Social Worker, National Rehabilitation Hospital
Dr. John Latham	General Practitioner, Dublin
Dr. Tim Counihan	Neurologist, Galway
Mr. Alexis Donnelly	MS Ireland
Ms. Shona Lee	Advance Nurse Practitioner, Rheumatology
Prof. Rose Ann Kenny	Consultant Geriatrician

SUB-GROUPS membership

Sub-group on Model of Care
Alma Joyce (*Lead*), Marion Meany and Elaine Whelan.

5 sub-groups on Needs Analyses

Sub-group 1: Acquired Brain Injury Needs Analysis
Dr. Jane Whelan (*Lead*), Dr. Aine Carroll, Michael Clavin, Barbara O'Connell, Dr. Salvatore Giangrasso and Anne O'Loughlin.

Sub-group 2: Cerebral Palsy Needs Analysis
Dr. Cara McDonagh (*Lead*), Dr. Tim Jackson, Dr. Owen Hensey, Dr. Jacinta McElligott and Service User Participation.

Sub-group 3: Multiple Sclerosis Needs Analysis
Dr. Anne Dee (*Lead*), Alexis Donnelly, Dr. Aine Carroll, Dr. Tim Jackson and Dr. John Latham.

Sub-group 4: Parkinson's Disease Needs Analysis
Julie Regan (*Lead*), Dr. Tim Counihan, Dr. Ina Kelly and Service User Participation.

Sub-group 5: Spinal Cord Injury Needs Analysis
Dr. Ina Kelly (*Lead*), Dr. Manus McCaughey, Anne O'Loughlin, Eugene Roe and Colm Whooley.

Appendix 2: List of submissions received

In total, 77 submissions were received from the following organisations and individuals (*latter arranged alphabetically by surname*):

- Adelaide and Meath Hospital Dublin incorporating the National Children's Hospital (AMNCH)
- Allied Health Professionals (AHPs) Group, Galway University Hospitals (GUH)
- Amputee Disability Federation Ireland
- Association of Occupational Therapists of Ireland (AOTI) – Mental Health Advisory Group
- Association of Occupational Therapists of Ireland (AOTI) – Rehabilitation Working Group
- AST Rehabilitation & Physiotherapy Clinic Ltd., Rushbrooke, Cobh, Co. Cork
- Barchester Healthcare Services Ltd.
- BRÍ
- Care Alliance Ireland
- CEART, Therapy, Rehabilitation and Health Support Services, Callan, Co. Kilkenny
- Central Remedial Clinic, Clontarf, Dublin 3
- Chronic Obstructive Pulmonary Disease (COPD) Outreach Programme, Beaumont Hospital
- Citizens Information Board
- Clontarf Adult Physical and Sensory Ability Team (CAPSAT)
- Cosgrove, Jim (Senior Music Therapist and Chairperson), Irish Association of Creative Arts Therapists (IACAT)
- Curran, Kevin (RMN), Community Nursing, MS Ireland, Carrickmacross, Co. Monaghan
- Disability Federation of Ireland
- Enable Ireland
- Fitzgerald, Alasdair (Consultant in Rehabilitative Medicine), Queen Elizabeth National Spinal Injuries Unit, Southern General Hospital, Glasgow
- Flood, Bernadette (Pharmacist)
- Gormley, Alice (Occupational Therapy Manager), Occupational Therapy Department, Cavan General Hospital
- Harford, Violet and Melly, Anne: Disability Services, HSE Dublin North East
- Headway
- Healy, Connie (Occupational Therapist), HSE Primary Care Services
- Hoban, Donal (Occupational Guidance Officer) and Brophy, Noreen (Case Manager), HSE West
- HSE, Acquired Brain Injury (ABI) Group
- HSE, Primary, Continuing and Community Care (PCCC), Audiology Services
- HSE, Primary, Continuing and Community Care (PCCC), North Tipperary/East Limerick Local Health Office
- Irish Association of Cardiac Rehabilitation (IACR)
- Irish Association of Rehabilitation Medicine (IARM)
- Irish Association of Speech and Language Therapists
- Irish Heart Foundation Council on Stroke
- Irish Hospice Foundation
- Irish National Audit for Stroke Care (INASC) Research Team
- Irish Nutrition and Dietetic Institute (INDI)
- Irish Society of Chartered Physiotherapists
- Kelly, Gracia Gomez (Occupational Therapy Manager), Mayo General Hospital
- Kiernan, Dr. Regina (Consultant in Public Health Medicine), Merlin Park, Galway
- Lennox, Selina (Senior Occupational Therapist), Arklow Primary Care Team
- Limerick Community Rehabilitation Team (CRT)
- Lynch, Kathleen, TD
- Mayo Head Injuries Support Group
- McGuire, Dr. Brian (Senior Lecturer in Clinical Psychology; Director, Clinical Training Programme; Joint Director, Centre for Pain Research), NUI Galway

- McLoughlin, Geraldine: Sunibhe, Ardcarn, Boyle, Co. Roscommon
- Moriarity, Eileen (Clinical Specialist Physiotherapist) and Sheehy, Jamie (Community Physiotherapist), North/South Lee Community Physiotherapy Service, HSE South, St. Finbarr's Hospital, Douglas Road, Cork
- Mullen, Maria; Hurley, Georgina; Power, Sheila; and Gamble, Mary: Physiotherapy Department, St. Luke's Hospital, Rathgar
- Multiple Sclerosis Society of Ireland
- Multiple Sclerosis Society, South Wexford Branch
- Murphy, Dr. Mary (Senior Medical Officer), HSE South, North Cork Community Service, Gouldshill House, Mallow, Co. Cork
- National Disability Authority (NDA)
- National Rehabilitation Hospital (NRH)
- Neurological Alliance of Ireland (NAI)
- O'Brien, Marita (PhD student), Social Policy and Ageing Research Centre (SPARC), Trinity College, Dublin
- Occupational Therapy Department, Mayo General Hospital
- Occupational Therapy Department, Sacred Heart Hospital, Castlebar
- O'Connor, Maire (Chairperson), National Respiratory (COPD) Strategy Group
- O'Neill, Dr. Colleen (Principal Dental Surgeon), HSE Dental Clinic, 10 Cornmarket, Dublin 8, and Clarke, Dr. David, HSE Dental Services, Our Lady's Clinic, Patrick Street, Dun Laoghaire
- Our Lady's Children's Hospital, Crumlin
- Peamount Hospital
- Peter Bradley Foundation
- Phelan, Ann (Councillor)
- Physical and Sensory Disability Department, Pearse Road, Letterkenny, Co. Donegal – ABI
- Physical and Sensory Disability Department, Pearse Road, Letterkenny, Co. Donegal – Neurological Rehabilitation Services
- Physiotherapy Services, Louth Hospital/Louth Primary, Continuing and Community Care (PCCC) Services
- Psychological Society of Ireland
- Rehab Group
- Royal Hospital Donnybrook
- Ryan, Sheila (Physiotherapy Manager), Clare Community and Primary Care; O'Shea, Niamh (Physiotherapy Manager), MWRH, Ennis; McTeague, Ethna (Speech and Language Therapy Manager); and Kitson, Claire (Occupational Therapy Manager), Clare Community and Primary Care
- Social Workers in Neuro Disability Interest Group, c/o National Rehabilitation Hospital
- Special Interest Group in Neuropsychology (SIGN), Psychological Society of Ireland
- St. Joseph's Centre for the Visually Impaired
- St. Vincent's University Hospital, Dublin
- Stroke and Medical Rehabilitation Unit, General Hospital, Letterkenny, Co. Donegal
- Stroke Rehabilitation Team, Baggot Street Community Hospital
- Talbot Group, Stamullen, Co. Meath
- Try-It Consortium
- Wall, Triona (Senior Occupational Therapist), St. Patrick's Hospital, John's Hill, Waterford, and O'Keeffe, Catherine (Occupational Therapy Manager), St. Luke's General Hospital, Kilkenny

Appendix 3: Current Neuro-Rehabilitation Service Providers

NATIONAL SPECIALIST NEURO-REHABILITATION SERVICE PROVISION

National Rehabilitation Hospital

The National Rehabilitation Hospital (NRH) is a supraregional (national) centre providing specialist neuro-rehabilitation services on an in-patient and out-patient basis for adults. It also provides neuro-rehabilitation services for children with acquired brain injury (ABI) including stroke, spinal cord injury (SCI), limb absence and other neurological conditions (*see 'Children's neuro-rehabilitation services' below*). These children are followed up and reviewed by the specialist paediatric team throughout their childhood as required.

Specialist adult services at the NRH include:

- In-patient complex rehabilitation assessment for physical and complex disabilities.
- Coma-arousal programmes, for patients in vegetative or minimally responsive states.
- Spasticity management through interdisciplinary programmes, including intrathecal baclofen pumps, *botulinum* toxin in conjunction with serial splinting/orthotic management/postural management programmes.
- Tracheo-pharyngeal management – tracheostomy weaning together with dysphagia assessment (video-fluoroscopy, FEES, etc).
- Electro-assistive technology/communication aids/computers in disability – application of state-of-the-art technology for improved independence and quality of life.
- Group therapy programmes allow patients to gain not only from therapy, but also from the experience of engaging with others who have similar problems. These group sessions may include social interaction, extended activities of daily living, awareness of current affairs, high-level communication skills and work skills.
- Behavioural/cognitive/neuropsychology rehabilitation programmes, either for 'walking-wounded' brain-injured patients or those with complex behavioural syndromes in association with physical disability.
- Cognitive behavioural therapy programmes, for chronic pain syndromes, chronic fatigue, conversion or 'enhanced disability behaviour' states.
- Neuro-behavioural programmes.
- Sexual counselling, for disabled people and their partners.
- Formalised family support, to educate, advise and facilitate family/carer function in the context of the patient's immediate and long-term dependency.
- Specialised education programmes for patients and families/carers, including insight and awareness programmes, stroke awareness for carers, aphasia education, meet-and-teach brain injury education for families with members who are out-patients.
- Complex discharge planning – Many people require continued support or are unable to return to their own homes and so require coordinated discharge planning, involving health, social services and often employment/education authorities.
- Back-to-work programmes, including vocational and social rehabilitation in the light of complex physical and sensory disabilities, work assessments, employer negotiations and financial counselling.

Referral to the NRH is via tertiary or acute hospitals, or through primary services. The NRH maintains close links with these services to best plan for timely admission of patients ready for this phase of neuro-rehabilitation. Table A3-1 provides a picture of the numbers of admissions to the NRH during 2008 and length of stay of patients requiring specialist neuro-rehabilitation. In-patient admissions were distributed across the 4 HSE Regions as follows: Dublin Mid-Leinster (33%), Dublin North East (19%), West (24%) and South (24%).

Table A3-1: Patient activity (adults) in National Rehabilitation Hospital, nationally and regionally (2008)

In-patient admissions		Day cases	Consultant-led out-patient activity	Non-Consultant-led out-patient activity
Brain Injury Non-traumatic	106	281	232	
Brain Injury Traumatic	147	160	308	
Spinal Injury	188	24	525	
Stroke Service	128	1	67	
Prosthetic Service	117	87	2,567	
Other Neurological	24	7	99	
Other Non-neurological	1	4	2	
Radiology (X-ray)	–	–	1,269	
Totals	711	564	5,069	6,654
Total No. of cases	**12,998**			

The NRH provides outreach services to the regions through professional links and field visits. Some services have been developed offsite in collaboration with the neurosciences services in St. Joseph's Unit of Beaumont Hospital.

The number of children who accessed the NRH paediatric service in 2008 were:

- ABI 180 children;
- Limb absence 40-50 children;
- SCI 18 children.

HOSPITAL BASED NEURO-REHABILITATION SERVICE PROVISION

Acute Tertiary Hospitals

Tertiary hospitals cater for patients in acute situations with high immediate neuro-rehabilitation needs. Neuro-rehabilitation in these settings is generally reported as being spread across neurology and neurosurgery, cardiac, respiratory, trauma/orthopaedic and rheumatological conditions.

Supraregional surgical centres for traumatic injury are located in certain tertiary hospitals – Beaumont Hospital in Dublin and Cork University Hospital are specialist centres for neurosurgery, while the Mater Hospital in Dublin is the specialist centre for spinal injury surgery. An additional neuro-rehabilitation unit at Beaumont Hospital (St. Joseph's) offers early neuro-rehabilitation for patients who are designated as being immediately post-acute care; this unit is supported by the National Rehabilitation Hospital (*see above*).

HSE South has recently appointed a full-time specialist in medical rehabilitation on a temporary contract and he will link with colleagues in the National Rehabilitation Hospital.

The national mapping exercise conducted for this policy found that access to neuro-rehabilitation services at this level was varied. In some tertiary hospitals, there were a wide range of out-patient neuro-rehabilitation services, while one hospital reported no out-patient access. Access through GP referral was less available, varying from access to some services (particularly physiotherapy) to none. Waiting list times also varied, from 'no waiting' to up to 8 months.

Information on core therapy disciplines in 7 of these specialised acute tertiary settings is shown in Table A3-2. It can be seen that certain services, such as psychology and social work, are not available in every tertiary hospital and also that some of the larger tertiary hospitals do not have speech and language therapists and occupational therapists. The reader should note that these figures *do not indicate the degree to which individual therapists have specialised in neuro-rehabilitation or in the care of specific conditions*.

Table A3-2: Number of whole time equivalent staff in 7 tertiary hospitals (2008)

Discipline and Staff category	Range	Mean	Median	Total
Physiotherapy				
Senior	11.8-23	18.7	18	**130.6**
Basic Grade	4-25.5	18.3	21	**128.2**
Clinical Specialist	0-4	1.7	1	**12**
Care Attendant/Assistant	0-9.1	3.4	2	**25.1**
Occupational Therapy				
Senior	5-12	8.6	8.5	**60**
Basic Grade	2-11	6.6	5.5	**46.5**
Clinical Specialist	0-2	0.9	1	**6.5**
Care Attendant/Assistant	0-3.2	0.9	0	**6.2**
Speech and Language Therapy				
Senior	3-7.3	5.4	5	**37.8**
Basic Grade	1-5.5	3	3	**21.5**
Social Work				
Senior	0-16.8	8	8	**55.8**
Basic Grade	0-17.5	8.9	9.5	**55.8**
Psychology				
Clinical Psychologist	0-7	2.1	0	**14.8**
Orthotists and Prosthetists	0	0	0	**0**

Acute Non-Tertiary Services

Non-tertiary neuro-rehabilitation services are spread across those patient groups provided for in each hospital. Access to neuro-rehabilitation services in these settings was reported as being varied (*see Table A3-3*). Non-tertiary hospitals provided greater out-patient access, with the majority providing out-patient neuro-rehabilitation, although some had variations of out-patient services by discipline. Those that did not provide out-patient services reported service provision by Primary, Continuing and Community Care (PCCC). Access through GP referral was frequent, but 5 of the 16 hospitals did not have access through primary care. Waiting times varied, from no waiting to 9 months.

Table A3-3: Number of whole time equivalent (WTE) staff in 16 non-tertiary hospitals (2008)

Discipline and Staff category	Range	Mean	Median	Total
Physiotherapy				
Senior	0-11.5	5.6	6.4	**90.2**
Basic Grade	0-14	5.6	5	**90.2**
Clinical Specialist	0-1.1	0.3	0	**5.6**
Care Attendant/Assistant	0-5	1.3	1	**20**
Occupational Therapy				
Senior	0-3.8	1.2	1	**19.8**
Basic Grade	0-4	1.4	0.5	**21.6**
Clinical Specialist	0	0	0	**0**
Care Attendant/Assistant	0-2.9	0.6	0	**9.9**
Speech and Language Therapy				
Senior	0-2	0.7	0.8	**10.5**
Basic Grade	0-1.8	0.3	0	**5.3**
Social Work				
Senior	0-1	0.3	0	**5**
Basic Grade	0-3.5	0.7	0	**11**
Psychology				
Clinical Psychologist	0	0	0	**0**
Orthotists and Prosthetists*	0-0.2	0.02	0	**0.25**

* Combined number of WTEs unknown as some reported ‘contracted in’ but did not specify time allocated.

Hospitals were asked about other relevant staff and several reported on numbers of dietetics staff, tutors and other educators and managers in different disciplines, e.g. physiotherapy manager.

It is not clear the extent to which the neuro-rehabilitation services provided in acute tertiary and acute non-tertiary hospitals and in the community meet best practice standards as regards interdisciplinary team care, specialist expertise and goal setting and planning. Similarly, the degree to which individual therapists are specialised in neuro-rehabilitation is a huge constraint on interpreting data as indicative of service provision. This requires to be addressed as part of a proposed regional assessment of existing care provision.

NEURO-REHABILITATION SERVICES IN THE COMMUNITY

While mapping of service provision at acute hospital level tends to be relatively straightforward, the numerous and varied services and multiple providers existing at community level make this a significantly more challenging task. Services related to neuro-rehabilitation at this level include physiotherapy, occupational therapy, speech and language therapy, residential and respite care, home support, and rehabilitative and vocational training. Supplementary information was also sought in the mapping exercise on neuro-rehabilitation facilities, access to services and waiting lists. Service provision at this level is delivered directly via HSE local health offices and associated HSE structures (*see below*), as well as by a range of non-statutory service providers contracted to deliver specific services or services targeted towards service users in specific diagnostic categories.

HSE-provided services

Neuro-rehabilitation services at local level are delivered directly by the HSE via its 32 local health offices (LHOs), spread geographically across the country. The mapping questionnaire for this policy was completed with varying levels of detail from LHOs, despite considerable effort on the part of the Working Group to ensure a complete mapping of service provision. Thus, the picture offered nationally of community-level provision can only be considered as incomplete and lacking necessary detail.

Services at primary and community level are characteristically based in different settings with varying degrees of specialised provision based on historical development, resource availability and prioritisation. Access to primary care neuro-rehabilitation services is generally through referral from consultants, GPs, public health nurses, acute hospitals and other clinical staff. Access by self-referral is facilitated in some areas. Settings for service delivery range from health centres and community hospitals, to service user's homes. The main service settings reported include:

- primary, community and continuing care (PCCC) uni-disciplinary therapy;
- primary care team multidisciplinary therapy;
- specialised community neuro-rehabilitation teams;
- consultant-led neuro-rehabilitation in continuing care facilities or community hospitals;
- non-consultant-led neuro-rehabilitation in continuing care facilities and specialised residential facilities;
- day hospital or day centre neuro-rehabilitation services.

While it is not possible to quantify accurately the numbers of people receiving neuro-rehabilitation services at local level, it was evident from the information received that significant numbers were awaiting services, while others were receiving certain services but were on waiting lists for additional services (*see Tables A3-4 – A3-6*). While service delivery through primary care teams is included in these figures, information in relation to specialised community rehabilitation teams is provided separately (*see section below*).

Table A3-4: Physiotherapy – Therapists allocated to rehabilitation, including delivery through primary care teams (2008)

	Physiotherapy Senior and Basic WTE value	No. of people accessing service in 2008	No. of people per Physio per annum in 2008	No. of people on waiting list in 2008	Population size
Nationally	81.11	14,157	175	1,189	4,239,902
HSE Dublin North East	29.13	5,857	201	881	927,410
HSE Dublin Mid-Leinster	18.6	2,306	123	0	1,216,848
HSE South	14.05	5,672	403	131	1,082,022
HSE West	19.33	322	17	177	1,013,622

Table A3-5: Occupational Therapy (OT) – Therapists allocated to rehabilitation, including delivery through primary care teams (2008)

	OT Senior and Basic WTE value	No. of people accessing service in 2008	No. of people per OT therapist per annum in 2008	No. of people on waiting list in 2008	Population size
Nationally	72.86	16,136	221	1,687	4,239,902
HSE Dublin North East	23.9	3,393	141	452	927,410
HSE Dublin Mid-Leinster	18.3	4,681	255	156	1,216,848
HSE South	12.21	4,384	359	594	1,082,022
HSE West	18.45	3,678	199	485	1,013,622

Table A3-6: Speech and Language Therapy (S&L) – Therapists allocated to rehabilitation, including delivery through primary care teams (2008)

	S&L Therapy Senior and Basic WTE value	No. of people accessing service in 2008	No. of people per S&L therapist per annum in 2008	No. of people on waiting list in 2008	Population size
Nationally	52.14	3,366	65	1,637	4,239,902
HSE Dublin North East	28.11	1,445	51	557	927,410
HSE Dublin Mid-Leinster	4.8	473	98	451	1,216,848
HSE South	4.54	541	119	68	1,082,022
HSE West	14.69	907	62	561	1,013,622

Specialist Community Rehabilitation Teams

Community rehabilitation teams provide a more specialised and intensive level of service than the primary care inputs discussed above. They have been developed to support the rehabilitation needs of older people, those recovering from stroke, those with physical disability and those with acquired brain injury.

There are 28 specialist community rehabilitation teams based around the country (formerly known as the District Care Unit Teams). The majority disciplines represented on these teams are physiotherapists (40 whole time equivalent (WTE) staff), occupational therapists (18 WTE), speech

and language therapists (5 WTE) and nurses (26 WTE). Other disciplines represented (although in very low numbers) include psychologist (1 WTE), neuropsychologist (0.5 WTE), therapy assistants (4 WTE), orthotist (1 WTE), social workers (3.6 WTE), rehabilitation assistants (2 WTE) and case managers (3.5 WTE). Most of the care provided by these specialist community rehabilitation teams would be focused on older people and be at best of moderate intensity. These teams could be enhanced through training, protocol use and links with more specialised services, and thus become a resource to those requiring neuro-rehabilitation services throughout the full adult lifecycle.

Community rehabilitation teams have specific criteria for access and provide services for a time-limited period. Available figures indicate that approximately 3,000 people were accessing services provided by these teams during 2008. Table A3-7 shows the number of specialised community rehabilitation teams (including ABI) at both national and regional level, together with respective population sizes.

Table A3-7: Number of Specialist Community Rehabilitation Teams (2008)

	No. of teams	Population size	Team per population size
HSE Dublin North East	13	927,410	1 per 71,339
HSE Dublin Mid-Leinster	7	1,216,848	1 per 173,835
HSE South	3	1,082,022	1 per 360,674
HSE West	5	1,013,622	1 per 202,724
Total	**28**	**4,239,902**	**1 per 151,425**

Tables A3-8 – A3-10 show the relatively limited input nationally from therapy staff into rehabilitation services through dedicated rehabilitation teams. Data also demonstrate variances between regions with regard to rehabilitation service provision.

Table A3-8: Physiotherapy – Specialist Community Rehabilitation Teams, including ABI (2008)

	No. of teams	Whole time equivalent value	No. of people accessing services in 2008	No. of people per Physio per annum in 2008	Nos. on waiting list in 2008
HSE Dublin North East	13	26.6	877	33	17
HSE Dublin Mid-Leinster	7	11.35	978	86	110
HSE South	3	2.2	150	68	10
HSE West	5	3	598	199	0
Total	**28**	**43.15**	**2,535**	**58**	**137**

Table A3-9: Occupational Therapy (OT) – Specialist Community Rehabilitation Teams, including ABI (2008)

	No. of teams	Whole time equivalent value	No. of people accessing services in 2008	No. of people per OT therapist per annum in 2008	Nos. on waiting list in 2008
HSE Dublin North East	13	8	729	91	37
HSE Dublin Mid-Leinster	7	6.75	548	81	94
HSE South	3	2	320	160	0
HSE West	5	4	60	15	0
Total	**28**	**20.75**	**1,657**	**80**	**131**

Table A3-10: Speech and Language Therapy (S&L) – Specialist Community Rehabilitation Teams, including ABI (2008)

	No. of teams	Whole time equivalent value	No. of people accessing services in 2008	No. of people per S&L therapist per annum in 2008	Nos. on waiting list in 2008
HSE Dublin North East	13	2.8	592	211	20
HSE Dublin Mid-Leinster	7	1.2	152	126	101
HSE South	3	1	534	534	5
HSE West	5	1.25	60	48	0
Total	**28**	**6.25**	**1,338**	**214**	**126**

The proposed regional analysis of existing service provision will need to assess the specialist capacity for neuro-rehabilitation and the competencies contained in these 28 teams.

HSE ABI services

The HSE ABI Group is an informal grouping of diverse staff working with people with acquired brain injury (ABI) and employed by the HSE in various parts of the country.

ABI may be mild, moderate, severe or very severe. There is tremendous variation in both type and severity of disability following ABI. For many people with ABI, especially those in rural areas, proximity to home and family is a major factor determining what may be the most appropriate services. Sometimes, needs are seen to be met most satisfactorily by local generic disability services, e.g. home support packages, day centres, FÁS and other employment services. The HSE needs to ensure that adequate education and training in relation to ABI is provided for staff employed by these generic services. A minority of individuals who have suffered ABI have needs of such range and complexity that they require full involvement of specialist ABI services.

When the person who has sustained an ABI is medically stable, he or she is ready for a period of acute rehabilitation. Much can be achieved at this stage. Needs change with time and individuals should have opportunities to have their needs reviewed and to be able to access appropriate services years after sustaining an ABI.

The manner in which the HSE meets its responsibility for ABI varies enormously from one local area to another across the country. In some areas (particularly in the South East and North West), the HSE takes direct responsibility for the delivery of some ABI services, while commissioning non-statutory agencies to provide other services. In other areas, such as in the North East, the HSE commissions virtually all ABI services from non-statutory agencies.

In the former South-Eastern Health Board area, the HSE has a specialist ABI team that both has direct contact with people with ABI and their families/carers, and also has a role in advising HSE managers in relation to services for particular cohorts and the more general development of ABI services. The HSE's South Tipperary Local Health Office runs a Community Rehabilitation Assessment and Transitional Living Unit, and also an ABI day and outreach service.

In the former North-Western Health Board area, the HSE's Donegal and Sligo/Leitrim Local Health Office areas are directly involved in the provision of ABI services. Donegal has been innovative in relation to the organisation of respite for people with ABI and has pioneered the development of Rehabilitative Training in collaboration with the local Regional Technical College. The HSE in Sligo/Leitrim has developed a Community ABI Rehabilitation Team that provides rehabilitation programmes, family support and a Transitional Living Unit; the HSE formed a partnership with the Peter Bradley Foundation for the delivery of the service. In the North East, case managers recruited by the Peter Bradley Foundation have been appointed in each HSE Local Health Office area.

The HSE ABI Group is in the process of developing a booklet detailing ABI services across the country, to be published shortly.

Non-acute neuro-rehabilitation beds

At sub-acute level, in-patient neuro-rehabilitation is reported as being delivered through community hospitals with referrals from consultants in acute settings to consultant geriatricians, psychiatrists or neurologists. Care provided by geriatricians is confined to those over the age of 65.

Nationally, there are 34 units with approximately 337 beds dedicated to rehabilitation services. These beds are primarily for older people (over 65); in some areas, people under 65 can access these services, but are only considered on a case-by-case basis. In 2008, approximately 2,552 people accessed these services. Disciplines represented in these services include physiotherapy (26.8 WTE), occupational therapy (32.2 WTE), speech and language therapy (6.54 WTE), nursing staff (117.35 WTE), healthcare attendants (56.05 WTE) and social workers (1.5 WTE).

Dedicated residential neuro-rehabilitation services

Residential services with a focus on providing a neuro-rehabilitation approach have developed primarily as a response to people with acquired brain injury or others requiring slow stream (less intensive care) neuro-rehabilitation.

There are approximately 534 dedicated rehabilitation beds provided nationally through the HSE, primarily by non-statutory service providers. Older people, those with acquired brain injury, those under 65 with physical disabilities and those with rheumatology are the main cohorts of people who access these dedicated rehabilitation beds. Some of the beds are also utilised for respite provision for children and adults. Many of these beds provide only low levels of rehabilitation.

Nursing homes

In 2008, a total of 388 people with neuro-rehabilitation needs were recorded as resident in HSE-contracted or HSE-funded nursing homes. It is reckoned that this number is a significant underestimate of the true numbers in nursing home settings needing neuro-rehabilitation input. Services provided to this group vary greatly between HSE Regions, but in general they are limited, with minimal therapy input and often restricted to provision of necessary equipment.

Clearly, the situation of young people with a long-term neuro disability in these nursing home settings (often very inappropriately) should be reassessed as part of an overall aim of ensuring that all people with neuro-rehabilitation needs are enabled to benefit from optimal neuro-rehabilitation service delivery.

SERVICES PROVIDED BY THE NON-STATUTORY SECTOR

As mentioned above, a number of neuro-rehabilitation services are provided, with funding from the HSE, at national level by non-statutory agencies, such as the National Rehabilitation Hospital (NRH) and the Central Remedial Clinic (CRC). However, the majority of neuro-rehabilitation services provided by the non-statutory sector are located at regional, primary and community levels. They form a vital part of the total level of service provision and range from in-patient specialised provision to information and support services for a variety of conditions.

The overall dedicated therapy input to neuro-rehabilitation services provided by the non-statutory sector during 2008 is summarised in Table A3-11.

Table A3-11: Summary of dedicated therapy input nationally by non-statutory sector (2008)

Staff category	Whole time equivalent value	No. of people accessing services in 2008	No. of people per therapist per annum	No. of people on waiting list
Physiotherapy	35.19	2,523	72	81
Occupational Therapy	25.3	1,884	74	105
Speech and Language Therapy	13.73	839	61	15
Psychology	9.5	545	57	203
Neuropsychology	6.2	149	24	67
Social Worker	9.9	687	69	51
Therapy Assistants	13.75	21	1.5	17

The work of the main non-statutory agencies involved in the provision of neuro-rehabilitation is described below.

Central Remedial Clinic

The Central Remedial Clinic (CRC) is a centre providing a comprehensive range of medical and therapeutic services for children and adults with physical disabilities. It is a leading provider of specialist services in gait analysis, specialist orthopaedics, assistive technology, eating, drinking and swallowing clinics, diet clinics, hydrotherapy and specialist seating. Table A3-12 shows the numbers of patients, both adults and children, accessing the range of services offered by the CRC in 2008.

In addition to the main centre in Clontarf, the CRC delivers services through regional campuses in Clondalkin, Limerick and Waterford, and on an outreach basis to Donegal, Letterkenny, Mullingar, Portarlington and Sligo. Two schools for children aged 3-18 are operated by the CRC, with full therapy and specialist services provided in each.

Table A3-12: Patient activity (adults and children) in Central Remedial Clinic, nationally and regionally (2008)

Service	No. of people accessing service in 2008	No. of people on waiting list for service	No. of people currently in receipt of service who require additional services	Average waiting time to access service (months)
Physiotherapy	1,995	81		3.0
Occupational Therapy	1,250	105		4.8
Speech and Language Therapy (SLT)	755	15		4.1
Clinical Specialist SLT	60			
Psychology (Clinical and Educational)	327	82		14
Orthotics/Prosthetics	557	44		4.4
Social Work	586	45		3.9
Assistive Technology and Specialised Seating	1,890	296		4.0
Eating, Drinking and Swallowing Clinic	206	44		2.5
Gait Analysis	318	84		4.0
Nursing	242	39		
Medical Services	1,960	101		1.5
Transition Programme – school-leavers	4	1	4	
Training and Development Workshop	67	3	35	
Day Activation	230	78	175	
Dietetics	558	15	15	3.0
Rehabilitative Training	24	12	7	
Home Support Services	68	12	35	

Access to CRC services is generally through maternity hospitals, children's hospitals, primary care and community services, non-statutory organisations, GPs and consultants. A number of departments within the CRC (AT, specialised seating, OT) take self-referrals or family referrals.

Acquired Brain Injury Ireland (formerly Peter Bradley Foundation)

Acquired Brain Injury (ABI) Ireland provides a range of HSE-commissioned specialised community rehabilitation services throughout Ireland across a national framework spanning 4 HSE Regions (*see Table A3-13*). Individualised rehabilitation planning ensures that the person served is fully involved in all decisions that affect his or her life. ABI Ireland has been accredited through the Commission for Accreditation Rehabilitation Facilities (CARF) for specialised Acquired Brain Injury Residential programmes and Home and Community Rehabilitation programmes.

Table A3-13: Number of people accessing services provided by Acquired Brain Injury (ABI) Ireland, by HSE Region (2009)

	East/ North East Region	South/ Mid-West Region	South-East/ Midlands Region	West/ North West Region
Residential	21	18	6	17
Community service (Outreach)	126	40	93	25
Day service	23	–	–	–
Case-managed individuals	214		75	30
Case-managed families	82	–	–	–
Family liaison	27	120	–	43
Pilot services	1	–	1	–
Respite	–	–	–	4
Total	**956**			

The following is a brief overview of the services ABI Ireland provided in 2009:

- **Supported living** – Home-from-home in the community: 14 residences across all HSE Regions, including a Transitional Living residence in Sligo. The Sligo clinical team is a unique partnership of a joint ABI Ireland/HSE team.
- **Community rehabilitation/Outreach services**: 15 services across all HSE Regions. These are individual rehabilitation programmes based in the community, where skills are relearned using the person's natural environment.
- **Case management**: 7 case managers in place – in Dublin East, Southwest and North, Cavan, Monaghan, Meath, Louth and the Midlands (Tullamore). A case manager acts as the single point of contact and provides a clear care pathway from acute settings through post-acute and into community rehabilitation.
- **Day resource service**: 3 such services, based on the Clubhouse Model, are located in Dun Laoghaire, with pilot projects in Kerry and South West Dublin.
- **Family support services** (including therapy groups, education and general support): 240 family carers are involved in ABI Ireland's ABI-specific 'Training the carer' programme, which is run over 6 days and offered in 16 regional locations.
- **Psychological services** (including assessment, counselling and programmes on cognitive rehabilitation, cognitive behavioural therapy and parenting): 3.5 whole time equivalent neuropsychologists are allocated to these services.
- **Home liaison/social work** (including counselling, mediation, community access, grief and loss support groups): 2.5 whole time equivalent social workers/family liaison staff are allocated to these services.
- **Neuro-occupational Therapy**: 1 whole time equivalent ABI team in the Midlands.
- **ABI awareness, information, training and education programmes** (both internal and external): ABI Ireland is working with the Academy of Certified Brain Injury Specialists (ACBIS) of the Brain Injury Association of America (BIAA) and 13 of ABI Ireland's staff have completed ACBIS's Certification of Brain Injury Specialists (CBIS) training programme. A further 2 of ABI Ireland's staff are being trained as trainers to help ensure that further ABI specialists receive this vital training.

- **Social group – Out-of-hours**: There are 2 such groups, operating in Waterford (in collaboration with Headway) and in Kerry (in collaboration with BRÍ).
- **Sexuality and relationship workshops**: These training sessions are run for people with ABI throughout the country across their residential and community rehabilitation outreach services. A forum of service users has been established to plan and develop the programme further.
- **Cognitive rehabilitation**: Group sessions are run for people with ABI.
- **Family and carers**: Parenting programmes for parents of children with ABI are run in Dublin.
- **Support groups**: 'Girls aloud' is a social support group for spouses and girlfriends of men with ABI.
- **Children's services**: 2 pilot projects are currently in operation.

BRÍ

BRÍ is an advocacy and support organisation for people with acquired brain injury (ABI) and their families and carers. It is run by people who have suffered a brain injury. It works to achieve change in service provision, awareness and prevention. This is achieved through group advocacy, information and support, lobbying, raising awareness and personal advocacy. These activities take place through BRÍ's group meetings held every month at local, regional and national level around the country. There is also a personal advocacy service, operating in the Dublin area and sponsored by the Citizens' Information Board, under the Disability Act 2005. During 2008, 25 people accessed BRÍ's service, of which 13 required additional services, with 3 on the waiting list.

Enable Ireland

Founded in 1948, Enable Ireland is a provider of services to 3,500 children and adults with disabilities and their families. Some of the services provided are early intervention services (0-5 years), children's services (5-18 years), community-based personal assistant (PA) services, day services and residential respite services.

Services for children and their families include all aspects of a child's physical, educational and social development from early infancy through adolescence. For adults, a range of services are provided covering personal development, independent living, employment and social and leisure activities. Services are offered through a combination of centre-based and outreach services, and include a range of therapeutic, educational, training, employment, personal assistance, advocacy and family support services.

Enable Ireland Dublin provides services in Sandymount, including early services, pre-school, school, school outreach team, respite and in-home support. Services are also provided in Tallaght, Kildare, Marino Clinic, Wicklow, Cork and Kerry, Galway and Mayo, Kilkenny and early services in Cos. Cavan, Monaghan and Meath. Schools for children aged 3-18 are also provided in Marino Clinic, Bray and Cork city.

Cheshire Ireland

Cheshire Ireland provides a range of supported accommodation, respite and personal support services to people with physical disabilities and neurological conditions. It provides residential/respite services (located at 22 units) and home support services (approximately 10,218 hours in 2008) across all HSE Regions.

Dystonia Ireland

Dystonia Ireland is a national support group for suffers of dystonia. The organisation was established in 1992 and aims to support, educate and raise awareness of the condition.

Brainwave

Brainwave is the national association dedicated to improvement in the quality of life for people with epilepsy. It operates from 10 regional centres and is primarily involved in the provision of information and advice, both to people with epilepsy and to healthcare professionals. It also works to promote public understanding of epilepsy, assists in research and promotes positive discrimination in favour of those affected by epilepsy.

Headway Ireland

Headway Ireland is a national association for acquired brain injury (ABI) and provides the following services:

- **Information and support helpline**.
- **Day rehabilitative services** (Dublin, Cork and Limerick): Headway runs a day services programme aimed at bringing together people with ABI to participate in a programme of activity tailored to meet their needs.
- **Rehabilitative training programme** (Dublin, Cork and Limerick): The ultimate goal of this programme is to develop independence for people with ABI in a personal, social and community capacity.
- **Psychological services** (Dublin, Cork, Limerick and Tralee): Psychological services comprise a range of assessments, group and individual therapies, and counselling, targeted at the needs of families experiencing ABI.
- **Supported employment service** (Cork and Dublin): The aim of this service is to facilitate people's re-integration into the labour market, at their optimal level with maximum independence.
- **Community access service** (Cork): This service aims to facilitate people with ABI to participate in activities in their own communities.

Huntington's Disease Association of Ireland

The Huntington's Disease Association of Ireland is a national non-statutory organisation established by Huntington's Disease family members to provide consultation, information and individualised support to those diagnosed with Huntington's Disease, as well as to their families and their healthcare teams. The organisation has one full-time and one part-time staff member.

Multiple Sclerosis Ireland

Multiple Sclerosis (MS) Ireland provides services at national, regional and local levels, as described below.

National MS Care Centre: At national level, MS Ireland has one residential centre – the MS Care Centre in Dublin. This is the only dedicated respite service for people with MS in Ireland and has a multidisciplinary team that includes an MS nurse specialist, a physiotherapist and an occupational therapist, providing the facility for assessment and review. The MS Care Centre also works actively with the hospitals and HSE primary care teams in order to facilitate early discharge from hospital where a period of extended rehabilitation and education is needed before returning to the community. The Care Centre has 12 beds (8 of which are funded by the HSE) and is open 50 weeks of the year. 450 clients accessed this service in 2008.

Regional MS offices: MS Ireland has 10 regional offices, mirroring the current HSE structure. In each regional office, the following priority areas (dealing broadly with rehabilitation for people with MS) are addressed:

- **Individual case plans**: The model of practice used by MS Ireland is a case management model, a process by which services are provided to an individual with MS that are coordinated across multiple service providers/agencies through the use of a case plan reflecting the person's needs. This is typically solution-focused, short-term and targeted. The case plan

supports the person through the transitional changes that MS presents and is also available to family members to help them deal with the many challenges they face as a family unit.

- **Education and Symptom Management Programmes** and **National Exercise and Health Promotion Project** ('Getting the Balance Right'): Community-based educational and symptom management programmes are planned regionally by MS Ireland to enable people with MS and their carers/families to make healthy life choices and promote positive mental health in a supportive environment. These programmes aim to support people to improve their coping strategies, with information provided on how to better manage the condition and take responsibility for their own health and well-being. Programmes include fatigue management, falls prevention, continence management, mobility management, carer education and support.
- **Counselling service**: MS Ireland has many trained counsellors and based on an assessment, a person with MS and/or a family member can be referred to counselling. This service offers people the opportunity of exploring the issues arising out of their diagnosis and the changes that they face as the disease progresses.

The MS Branch Network: MS Ireland has a network of 41 voluntary branches throughout the country and continues to be a great resource to the HSE community services. The role of the branches is to support people with MS through providing financial advice, therapeutic interventions (e.g. physiotherapy, yoga) and a social network for individuals and their families. The branches fund sessional therapies in collaboration with local HSE personnel and regional workers so as to avoid duplication. They can also fund equipment following an assessment from the community occupational therapist. In addition, they support the provision of personal assistance hours to augment the HSE allocations.

National MS Helpline: The MS Helpline, run by MS Ireland, provides a LoCall service for people with MS, their families, friends and colleagues, covering a wide range of information on topics related to MS, its treatments and management, and support on all aspects of living with the condition. The helpline is staffed by a team of trained professionals who are on hand to talk and, more importantly, to listen.

Muscular Dystrophy Ireland

Muscular Dystrophy Ireland (MDI) is a national organisation providing support and information to people with muscular dystrophy and their families. The Head Office in Dublin manages the provision of a range of supports nationwide, including:

- the provision of information;
- information meetings and conferences;
- research updates;
- publication of a newsletter and website;
- transport.

MDI also has youth programmes aimed at:

- empowering young members;
- encouraging meaningful participation;
- providing an educational aspect;
- promoting equality of opportunity;
- providing respite to members and carers.

At local level, MDI has 8 family support workers, 5 youth/respite workers and 10 respite care workers. The family support workers provide personal contact and support to people with neuro-muscular conditions and their families. In many cases, they are the sole point of contact for members so this support service is invaluable.

National Council for the Blind of Ireland

The National Council for the Blind of Ireland (NCBI) provides a range of services to over 8,000 people annually who are blind or visually impaired. It has a training centre in Dublin and 7 regional resource centres, supported by community resource workers (41.3), technology trainers (9.3), team managers (7) and clerical officers (7).

All the domiciliary and community-based services provided by the NCBI can be described as rehabilitative. Most rehabilitation for visually impaired people entails a combination of environmental adaptation and compensatory strategies to help improve their independent functioning, often combined with counselling to address the psycho-social aspects of losing one's sight. Assessment and services are provided in the environment within which the person will operate, whether it be at home, in the community or workplace, or in the NCBI Resource Centre.

National Learning Network

The National Learning Network provides rehabilitative training (HSE-funded) and vocational training (FÁS-funded) at 50 locations throughout the country. In 2009, 88 people considered to have physical and sensory disability, including brain injury, were accessing the rehabilitative training programmes. In addition, a further 691 people with similar disabilities attended vocational training programmes. In 2008, 90% of those completing the rehabilitative training programmes progressed to either employment or further training or education. This figure rose to 92% for those completing the vocational training programmes.

Peamount Health and Social Care Services

Peamount Health and Social Care Services is an independent non-statutory organisation funded by the HSE to provide health and social care services to people over 18 years of age. It provides post-acute rehabilitation within its Age Related Services (25 beds) and Respiratory Services (25 beds). It has joint consultant appointments with the Adelaide and Meath National Children's Hospital and referrals for rehabilitation are predominantly from that hospital, although access by other acute hospitals is promoted and pursued. Continuing care services are provided on-site to individuals with an age-related neurological disability and those with an intellectual disability.

Post Polio Support Group

The Post Polio Support Group focuses on maintaining the independence and dignity of polio survivors, supporting them at work, in the home and in other aspects of their daily lives. There are over 7,000 polio survivors in Ireland. About 60% of them may be experiencing the late effects of polio or post-polio syndrome, which can occur many years after the original infection.

The Post Polio Support Group creates awareness and provides information on the lasting effects of polio among polio survivors and the wider medical profession. Research is ongoing worldwide and members are kept up to date through newsletters and at seminars and conferences.

Rehabcare

Rehabcare is a national non-statutory agency delivering healthcare and social services across all HSE Regions, including:

- 24-hour residential support and longer term rehabilitation for people with severe acquired brain injury (ABI);
- a transitional living unit;
- a specialist outreach support service;
- residential respite services;
- home support services;
- day services;

- supported accommodation;
- home-based services;
- resource centres;
- residential services;
- in-home respite services for people under 65 with physical and sensory disabilities.

Royal Hospital Donnybrook – Adult Rehabilitation

Adult rehabilitation is one of the key services offered at the Royal Hospital Donnybrook (RHD). Led by a consultant in rehabilitation medicine and based around 12 beds, the service specialises in longer term, slow stream rehabilitation, lasting more than 3 months. Patients undertake a structured programme of therapy with the interdisciplinary team; individual goals are set and patients work closely with the whole team to achieve these goals. Discharge planning commences immediately post-admission and the team works with each patient to find the appropriate accommodation and supports needed to leave the hospital.

Wherever possible, patients are accommodated in the Phoenix Unit, which is a ward with self-catering facilities and specifically designed to facilitate independent living skills. Patients in Phoenix are encouraged and supported to cook for themselves (and their fellow-patients) and to undertake a full range of domestic tasks, including their own laundry. Patients may also have periods in the Transition Lodge, a self-contained wheelchair-accessible cottage in the grounds of the Royal Hospital. Here, they can practise the skills required for independent living or can perhaps learn new ways with the support of their carers.

In November 2007, the RHD's Phoenix Rehabilitation Unit won first place in the Reconfiguration Category of the HSE 'Better Service Awards' in the Dublin Mid-Leinster Region. The project went on to participate in the HSE 'National Achievement Awards', which took place in Dublin's Mansion House in April 2008. These awards brought together the HSE 'Innovation' and 'Quality and Safety' awards for the first time.

Spinal Injuries Ireland

Spinal Injuries Ireland is a national organisation providing supports to people with spinal cord injury. A range of services are provided, including:

- Drop-in Resource Centre, located in the grounds of the National Rehabilitation Hospital.
- Venture Programme, a social and activities programme designed to increase participation. Activities include kayaking, scuba-diving and self-defence.
- Support services, vocational programme and outreach services, with approximately 9 whole time equivalent staff supporting this area.

CHILDRENS' NEURO-REHABILITATION SERVICES

Nationally, neuro-rehabilitation services for children are provided by the HSE or by the non-statutory sector acting in partnership with the HSE. These services are provided supraregionally primarily through the tertiary services offered by the National Rehabilitation Hospital (NRH) and Enable Ireland. The NRH is an in-patient setting with specialist expertise in acquired brain injury (ABI) including stroke, spinal cord injury (SCI), limb absence and other neurological conditions. The Central Remedial Clinic (CRC) provides services in many areas to a wider group of children, including those with congenital conditions such as cerebral palsy. The NRH and the CRC collaborate in the provision of step-down rehabilitation facilities and in the provision of respite.

Within HSE primary and community services, neuro-rehabilitation services are provided through the Early Intervention and Children's Therapy teams, which provide assessment and intervention services to children with a wide range of disabilities, including developmental delay.

Tables A3-14 and A3-15 provide some information on service provision for children aged from birth to 18 years. Figures refer to early intervention services for all children across the disability spectrum (i.e. they do not represent HSE services to children with specific conditions such as cerebral palsy or muscular dystrophy). A significant proportion of intervention is provided in a unidisciplinary manner, which does not fit with the multidisciplinary team approach.

Table A3-14: Early intervention services for children aged 0-5 years (2008)

	HSE			Non-statutory service providers		
	Whole time equivalent staff	**No. of children 0-5 years accessing services in 2008**	**No. of children on waiting list**	**Whole time equivalent staff**	**No. of children 0-5 years accessing services in 2008**	**No. of children on waiting list**
Physiotherapy	24.02	1,158	92	24.61	945	57
Occupational Therapy	24	1,343	188	28.3	793	106
Speech and Language Therapy	34.85	2,824	111	28.2	640	65
Clinical Psychology	5	95	30	7.6	761*	22
Neuropsychology	0	–	–	2.48	200	–
Social Worker	2	132	0	8.83	503	39
Nursing	3	252	30	0.5	–	–
Paediatrician	0.5	–	–	–	–	–
Therapy Assistants	–	–	–	4	–	–

* This relates to attendances rather than attendees.

Table A3-15: Services for children aged 5-18 years (2008)

	HSE			Non-statutory service providers		
	Whole time equivalent staff	**No. of children 5-18 years accessing services in 2008**	**No. of children on waiting list**	**Whole time equivalent staff**	**No. of children 5-18 years accessing services in 2008**	**No. of children on waiting list**
Physiotherapy	27.1	1,248	145	37.74	820	37
Occupational Therapy	42.03	2,258	842	31.4	798	96
Speech and Language Therapy	27.14	5,757	852	21	386	38
Clinical Psychology	4.1	60	–	11.41	642*	114
Neuropsychology	–	–	–	1.6	–	–
Social Worker	4	55	–	9.61	679	11
Nursing	3.9	–	–	4.32	75	–
Paediatrician	–	–	–	–	–	–
Therapy Assistants	–	–	–	6.34	20	–

* This relates to attendances rather than attendees.

SUPPORT SERVICES

In addition to the services mentioned above, a range of additional services also exist for people with neuro-rehabilitation needs. The majority of these services are provided by the non-statutory sector and include:

Rehabilitative training places: In 2008, about 320,821 hours of rehabilitative training were provided by the non-statutory sector to 353 people, with a further 4,834 hours provided directly by the HSE to 283 people. Disability support services in universities are also a valuable resource.

Home Support Services: These services are primarily provided directly by the HSE, with approximately 785,215 hours provided to 1,802 people during 2008. A further 37,812 hours were provided by the non-statutory sector to 190 people.

Personal Assistants: Personal Assistants are provided by both the HSE and the non-statutory sector. In 2008, a total of 77,068 hours were provided to people.

Rehabilitation Assistants: 22 people in 2008 accessed HSE-funded rehabilitation assistant services (1,920 hours). In addition, the non-statutory sector provided 137 people with such services (19,891 hours).

Family Support Services: These services are provided through the non-statutory sector. In 2008, 25 people accessed 950 hours of service.

Respite: Approximately 75,449 hours of non-residential respite was provided to 1,480 people in 2008 through the non-statutory sector. In addition, this sector also provided home respite services (5,980 hours) to 68 people. The HSE directly provided 11,760 hours of respite to 301 people in 2008. It is recognised as being difficult for certain groups to access respite services, such as adults and children with ABI who are physically well, but who have behavioural difficulties.

National Assistive Technology (AT) Training Service: An organisation in the non-statutory sector provides assistive technology training, both certified and customised, to a range of internal and external stakeholders. It utilises a ‘train the trainer’ model, whereby it seeks to optimise access to appropriate AT for people with disabilities.

Day Services/Resource Centre: The non-statutory sector provided these services (25,200 hours) to 807 people during 2008.

NOTES

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