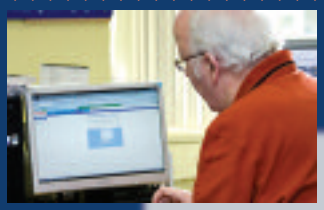
SUBMISSION TO:

Department of Health and Children and Health Service
Executive Working Group for the development of:

National Policy/Strategy for the Provision of Rehabilitation Services

January, 2009





National Rehabilitation Hospital
UNDER THE CARE OF THE SISTERS OF MERCY

NRH has been accredited by CARF

SUBMISSION TO:

Department of Health and Children and Health Service Executive Working Group for the development of:

National Policy/Strategy for the Provision of Rehabilitation Services

January, 2009

CONTENTS

National Rehabilitation Hospital

UNDER THE CARE OF THE SISTERS OF MERCY

Executive Summary

For patients with a disability, rehabilitation sits at the interface of a range of necessary services, from acute care to ongoing community care and disability services. With established expertise in multidisciplinary care planning and delivery, rehabilitation services have the potential to play a key role in better coordinating the patient journey across these streams of care and ensuring that each patient receives the right services at the right time. That potential can only be realised through the effective implementation of a national rehabilitation strategy.

The NRH believes the Working Group for the Development of National Policy/Strategy for the Provision of Rehabilitation Services has an opportunity and responsibility to develop a strategy document to:

- Clarify and map the role of rehabilitation services as an integral and essential component within the healthcare continuum in Ireland
- Develop an appropriate policy framework that can lead to the common understanding and leadership for the future development of rehabilitation services in the context of a national public healthcare system
- Develop a strategy for quality service provision and a preferred model of care that shows clearly demonstrated commitment and direction of service planning and resources to meet the current and future rehabilitation needs of Ireland
- Recognise and support the importance of rehabilitation data collection and management, and rehabilitation research across the country as investments in enhancing potential and quality of life
- Bring forward clear recommendations of how rehabilitation services should be organised, configured, developed and managed in an integrated holistic model of care
- Develop a role for a senior healthcare individual to take overall responsibility to develop the Strategy and rehabilitation agenda moving forward in a measurable action plan which can be assessed against objectives set. Government involvement is essential in order to ensure adequate support through policy and legislation, and to ensure strengthening of referral services. All shareholders must collaborate for the co-ordination of services, but it is internationally recognised that it is preferable if government takes a leading role in this.

- Establish a national agreement on the following issues;
  - Achieving the minimum number of in-patient Rehabilitation beds, with a minimum of 30 beds per 100,000 designated rehabilitation beds across adult and care of the elderly specialties. A lack of rehabilitation capacity results in inappropriate usage of acute care beds and delays in discharge from acute care.
  - Agreeing minimum allied health therapy levels in inpatient rehabilitation. This is recognised practice internationally and is in the order of 12 – 15 hours of therapy per week.
  - Standards on therapy levels need to be based on the significant body of international research which demonstrates that better outcomes and efficiency are achieved with more intensive therapy.
  - National agreement on models of care that provide the early commencement of rehabilitation where appropriate, allowing rehabilitation to begin before medical stability is achieved. This should include establishing standards on the minimum number of rehabilitation beds located within an acute hospital or acute hospital campus.
  - National agreement to establish comprehensive ambulatory (outpatient and community) rehabilitation programs at a level that allows for rapid discharge from inpatient rehabilitation as well as for patients who require rehabilitation but do not need to receive rehabilitation on an inpatient basis.
  - National reporting and benchmarking of rehabilitation access, quality and outcomes.

Section A

What is Rehabilitation?

A.1 DEFINITION OF REHABILITATION:

- There have been many definitions published for rehabilitation, and whatever definition is used in the eventual published strategy document, it is likely to be contentious. This debate is, perhaps, due to the fact that many people, or service providers, have many differing concepts, opinions and priorities when asked what rehabilitation is. Some examples to illustrate this are:

- The British Society of Rehabilitation Medicine (Turner-Stokes, 2003) defined rehabilitation in terms of both a concept and a service:

  CONCEPTUAL DEFINITION: *A process of active change by which a person who has become disabled acquires the knowledge and skills needed for optimal physical, psychological and social function.*

  SERVICE DEFINITION: *The use of all means to minimise the impact of disabling conditions and to assist disabled people to achieve their desired level of autonomy and participation in society.*

- The World Health Organisation (WHO, 2002) defines rehabilitation as:

  Rehabilitation of people with disabilities is a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides disabled people with the tools they need to attain independence and self-determination.

- Regardless of which definition is ultimately agreed, the definition should be established and standardised to give clarity of terms for all service providers and users within the Irish context. It is also important to clarify definitions of rehabilitation services.

A.2 TYPES OF REHABILITATION SERVICES

A.2.1 General Rehabilitation

All services caring for patients with disabling conditions have a responsibility to provide a rehabilitative approach. These skills should be a core competency of every healthcare professional (Turner-Stokes, 1999)

A.2.2 Specialist Rehabilitation Service (SRS)

Specialist Rehabilitation Service (SRS) is the total active care of patients with a disabling condition, and their families, by a multi-professional team who have undergone recognised specialist training in rehabilitation (Turner-Stokes, 2001)

An SRS service has the characteristics of:

- SRS can occur in all settings (i.e. from the hospital, to the community and the home), patient demographics may dictate the organisation of this service (paediatric, adult and geriatric) and types of service levels (inpatient, outpatient or community service).
- Some disabling conditions require SRS for particular diagnosis/conditions (i.e. an inpatient, outpatient or community brain injury Specialist Rehabilitation Service).
- Some disabling conditions present with particular difficulties at particular stages in life and require specific SRS to address these (i.e. an inpatient paediatric spinal injury Specialist Rehabilitation Service).
- The SRS team is supported/led by a consultant who is trained and accredited within the specialty of rehabilitation medicine.
- The team works in an inter-disciplinary, coordinated fashion towards an agreed set of goals to assist the patient to achieve their desired level of independence, autonomy and participation in society.
- It carries a more complex caseload than non-specialist services and has the required facilities, skills and specialist staffing to provide rehabilitation at a level of intensity commensurate with the patients' needs.
- It routinely monitors input and outcome data for the purpose of benchmarking and quality monitoring and provides systematically reported data on caseload, throughput and clinical outcomes.
- The SRS is a resource for advice, support, training and education to other professional staff providing support to local community rehabilitation services in the management of patients with complex disabilities.
- It serves a recognised role in education, training and published research for development of specialist rehabilitation in the field.

A.2.3 Complex Specialised Rehabilitation Services (C-SRS)

"A service for patients with severe complex disabilities whose rehabilitation needs are beyond the scope of their specialisist rehabilitation services and is best commissioned collaboratively" (Turner-Stokes, 2001)

These services are designed for persons with injury or illness resulting in complex and often multiple disabilities. They are high-cost, low-volume services given the incidence and prevalence of complex disabilities in the population.

Some specific examples of injury or illness associated with C-SRS include:

- Acquired Brain Injury
- Severe neurological illness or injury (e.g. Multiple Sclerosis, Guillain Barre Syndrome, and Motor Neurone Disease)
- Spinal Cord Injury
- Amputation or limb loss
- Persons with challenging behavioural manifestations.

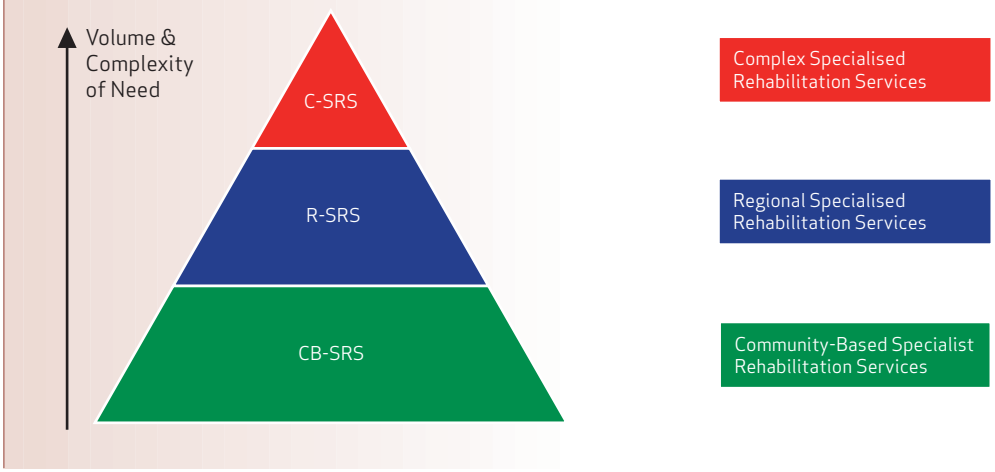
Accordingly to Turner-Stokes, (2001) the major characteristics of C-SRS are that:

- Most C-SRS offer rehabilitation across a range of service settings including inpatient, outpatient, day and community settings
- Staff have specialist training and experience
- Staffing levels are sufficient to provide complex, high intensity and longer duration services
- They operate in a highly co-ordinated inter-disciplinary manner
- They have speciality equipment and facilities consummate to needs
- They provide research, support education, research and training to other less specialised rehabilitation and community services.

Some examples of specific programmes offered by Complex Specialised Rehabilitation Services include:

- Inpatient complex rehabilitation assessment
- Coma-arousal programmes
- Spasticity management
- Tracheo-pharyngeal management
- Assistive technology (e.g. communication aids / computers in disability)
- Group therapy programmes
- Behavioural / cognitive / neuropsychology rehabilitation programmes
- Cognitive behavioural therapy programmes
- Sexual counselling
- Formalised family support
- Complex discharge planning and back to work programmes.

Figure 1: Levels of Specialised Rehabilitation Services



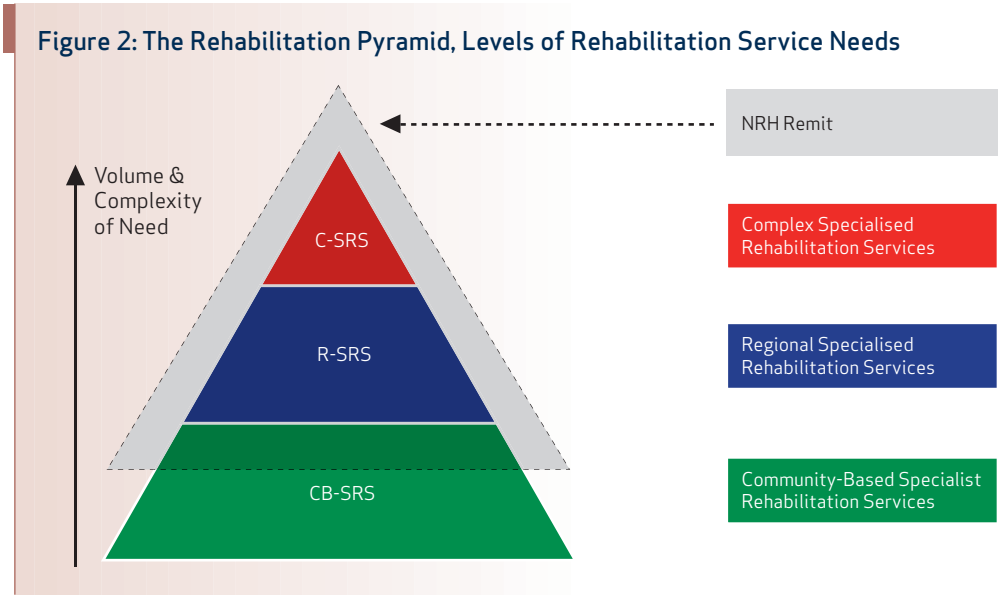
Section B

About the National Rehabilitation Hospital (NRH)

- The National Rehabilitation Hospital (NRH) is a publicly funded rehabilitation hospital that was founded in 1961 by the Sisters of Mercy. The NRH endeavours to maintain the ethos and mission on which the hospital was established.
- The NRH provides interdisciplinary Complex Specialised Rehabilitation Services (C-SRS) programmes for inpatients and outpatients from throughout the country, who have acquired a physical or cognitive disability as a result of an accident, illness or injury. In addition, NRH provides Specialist Rehabilitation Services (SRS) for patients on a local and regional basis.
- Persons are admitted with a range of conditions including stroke, traumatic and non-traumatic brain injury, spinal cord injury/dysfunction, amputation, limb absence, neurological disorders, musculoskeletal disorders and other conditions that may significantly limit physical, cognitive, emotional and behavioural functioning.
- The NRH provides personalised treatment plans dedicated to returning patients to the highest level of independence possible following their injury.
- The NRH offers four Complex Specialised Rehabilitation Service (C-SRS) programmes that are tailored to meet the individual needs of adult and paediatric patients in the following areas of specialty.
  - **Brain Injury** (including traumatic and non-traumatic brain injury, stroke, and other neurological conditions)
  - **Spinal Cord System of Care** (including traumatic and non-traumatic spinal cord injury)
  - **Prosthetic**, Orthotic and Limb Absence Rehabilitation (POLAR)
  - **Paediatric** Family-centred Rehabilitation.
- Categories of patients currently not within the NRH's current scope of service:
  - Relapsing and progressive neurological
  - Rapidly progressive brain tumours
  - Medically unstable (not "rehab ready")
  - Ventilator dependent patients who require 24 hour anaesthetic cover
  - Patients who are not referred
- In the NRH, there are currently 6 Consultants in Adult Rehabilitation Medicine and 1 for Children for a population of 4.2 million, all of whom admit to the NRH. The international recommendations are for at least 14 Consultants for our population.

- The NRH delivers specialist rehabilitation services at a national, regional and community service level, at the 3 levels of complexity as shown in Figure 2.
- At the NRH, the C-SRS delivers various rehabilitation programmes such as:
  - Coma-arousal programmes
  - SMART (Sensory Modality Assessment and Rehabilitation Technique)
  - Spasticity management
  - Assistive Technology (AT)
  - Dysphagia management
  - Group therapy programmes
  - Behavioural / cognitive neuropsychology / therapy rehabilitation programmes
  - Sexual counselling
  - Formalised family support
  - Complex discharge planning and vocational programmes.

Figure 2: The Rehabilitation Pyramid, Levels of Rehabilitation Service Needs



- The NRH also has an extensive education and research mandate and is actively engaged in education programmes aimed at the 3 levels of complexity, for local and regional providers of healthcare and for patients and family (Appendix Two: Listing of NRH Links and Affiliations with other Rehabilitation providers; Appendix Three: Registry of Research in Progress and Completed at the NRH).
- As part of our strong belief in ensuring the quality of our SRS and C-SRS, in June 2008 the NRH sought and achieved a maximum three-year accreditation for excellence in its provision of rehabilitation services from CARF (Commission for Accreditation of Rehabilitation Facilities). The awarding organisation, CARF is a non-profit organisation operating in Europe, US and Canada. This accreditation recognises that the NRH meets internationally recognised standards of performance in rehabilitation. Moreover, CARF accreditation provides the tool for ongoing quality improvement within the NRH.

B.1 QUICK FACTS ABOUT NRH

35,000

Over the last 48 years the NRH has cared for over 35,000 in-patients from throughout Ireland.

250,000

During this time, we have reviewed in excess of 250,000 persons in our out-patient services

Currently the allocation of in-patient beds are:

- Brain Injury Programme, including Stroke — 47 beds
- Spinal Cord System of Care — 38 beds
- Prosthetic, Orthotic and Limb Absence Rehabilitation (POLAR) — 17 beds
- Paediatric Family Centred Rehabilitation — 8 beds

110

Our current inpatient capacity is 110 beds; this is down from a potential maximum of 121 inpatient beds. Eleven beds were closed due to funding cutbacks from October 2007.

153

As of January 2009, we had a total of 153 patients (all age categories) on the waiting list for inpatient rehabilitation with the following breakdown per category:

- Brain Injury Programme (including 18 Stroke patients) — 83
- Spinal Cord System of Care — 46
- Prosthetic, Orthotic and Limb Absence Rehabilitation (POLAR) — 17
- Other Neurological conditions — 7

37,810

In 2008, we had a total of 37, 810 Inpatient Bed Days.

In 2008, the regional HSE % distribution of our inpatient admissions was:

- HSE Dublin Mid Leinster — 33%
- HSE West — 24%
- HSE South — 24%
- HSE Dublin North East — 19%

In 2008, we had an average length (days) of inpatient stay per programme of:

- Brain Injury Programme 57
- Stroke 91
- Spinal Cord System of Care 111
- Prosthetic, Orthotic and Limb Absence Rehabilitation (POLAR) 49

In 2008, the percent age distribution of inpatient admission

- < 65 years old was 86%
- > 65 years old was 14%

In 2008, the % total discharges per inpatient Programme was:

- Brain Injury Programme total 53%
- Spinal Cord System of Care 25%
- Prosthetic, Orthotic and Limb Absence Rehabilitation (POLAR) 19%
- Paediatric Family Centred Rehabilitation Programme 3%

In 2008, the inpatient discharge destination was

- Discharged Home 80%
- Back to Acute Hospital for non-medical reasons 10%
- To residential /nursing care 10%

90%

In 2007, 90% of our inpatient admissions were from the acute hospital network and 10% from primary care services.

In 2007, we had a total of 739 inpatient admissions with a breakdown per category:

- Brain Injury Programme total 404 (including Stroke, 119)
- Spinal Cord System of Care 180
- Prosthetic, Orthotic and Limb Absence Rehabilitation (POLAR) 109
- Other Neurological conditions 37
- Other non-Neurological conditions 9

12,231

In 2007, we had a total of 12,231 patients' visits for outpatient clinics

Section C

NRH Recommendations

Summary List of Recommendations

C.1 The NRH stongly recommends and supports the development of a National Policy/Strategy for the Provision of Rehabilitation Services in Ireland

C.2 The NRH recommends that all rehabilitation services need to be recognised as an integral component in the Irish Health Care system

C.3 The NRH recommends that a comprehensive rehabilitation needs assessment and service mapping of existing rehabilitation services be undertaken as a vital component of the Strategy

C.4 The NRH Proposed Model System of Rehabilitation Services

C.5 The NRH recommends the development of a comprehensive and integrated regional and national specialist rehabilitation services network

C.6 The NRH recommends the need for Community Based Specialist Rehabilitation Services (CB-SRS) and Continuing Care Services (CCS) development

C.7 The NRH proposed management and reporting structure for a comprehensive and integrated regional and national specialised rehabilitation services network

C.8 The NRH recommends the appointment of an international independent expert to assist in the development and implementation of the Rehabilitation Strategy

C.9 The NRH recommends the development and implementation of a Quality and Accreditation Framework for all Rehabilitation services

C.10 The NRH recommends the development of a National Rehabilitation Services Workforce Plan

C.11 The NRH recommends investment in education and research into rehabilitation

C.12 The NRH recommends the development of coordinated data collection systems specific to Rehabilitation services

C.1 THE NRH STRONGLY RECOMMENDS AND SUPPORTS THE DEVELOPMENT OF A NATIONAL STRATEGY FOR THE PROVISION OF REHABILITATION SERVICES IN IRELAND

- Significant government efforts made in the past decade to restructure the management and delivery of the health service as a whole in Ireland have lead to some changes in the rehabilitation sector. Some initiatives have focused on improving the effectiveness and quality of services; and some on improving integration among all components (i.e. inpatient, outpatient/outreach, in-home services) and levels (i.e. prevention and promotion, restorative, supportive, palliative) of rehabilitation. However, without a specific national policy and strategic plan to improve rehabilitation services in Ireland, these efforts have been slow to happen, uncoordinated and regional. Furthermore, lack of clear policy and planning has lead to inconsistent philosophies, principles, definitions and quality standards for rehabilitation throughout the country.
- Since the early 1990's, the NRH has strongly advocated the need for Ireland to have an all embracing, comprehensive strategy in place for the provision of rehabilitation services.
- This belief was highlighted by the NRH hosting a two-day conference in October 2002 titled 'Developing a National Strategy for Rehabilitation Services in Ireland'. This conference had numerous national and international experts in clinical and management fields of rehabilitation speaking on the need for the development of a comprehensive rehabilitation strategy (copies of conference presentations are available from the NRH).
- The formation of the strategy must also take into account the changing expectations of the Irish population in delivery and performance of all health services, including rehabilitation. It must respond to the expectations of users and providers that need rehabilitation to be:
  - More equitable in its response to users
  - More demanding of amount and variety of services in the community and closer to home
  - More aware of and responsive to rehabilitation needs across the care continuum
  - More concerned with providing adequate education and information
  - More concerned with choice and person-centred practice
  - More reliant on evidence-based practice and outcomes
  - More fully integrated with other parts of the health, disability, employment and community care systems.

C.2 THE NRH RECOMMENDS THAT ALL REHABILITATION SERVICES NEED TO BE RECOGNISED AS AN INTEGRAL COMPONENT IN THE IRISH HEALTH CARE SYSTEM

- Rehabilitation plays a vital role in preserving and enhancing the quality of life and functional independence of individuals but the field of rehabilitation is changing in significant ways.
- Rehabilitation is shown to be effective in enhancing individual functioning and independent living by achieving greater activity, better health and by reducing complications and the effects of co-morbidities. This leads to several benefits to the individual and to society, which includes greater personal autonomy, improved opportunities for employment and other occupational activity.
- Rehabilitation is also an integral component of all other health services (e.g. acute care, long- term care, mental healthcare, and home care). It has taken on a greater importance in a restructured health system supporting shorter hospital lengths of stay, reducing re-admissions, physician/GP visits and A&E visits.
- Increases in the demand for rehabilitation services are being driven, in part, by changing demographics, increased population, the prevalence of disabling and chronic conditions in the population, and changing patterns in the use of rehabilitation services. Increases in life expectancy, combined with rapid growth in the elderly population, suggests increased demand and associated costs to the healthcare system to meet the long-term care needs of this population.
- There is a large body of evidence for the effectiveness of rehabilitation and a growing body of evidence to support the cost effectiveness of rehabilitation. Effective rehabilitation interventions initiated early on can enhance the recovery process and minimise functional disability. Improved functional outcomes for patients also contribute to patient satisfaction and reduce potential costly long-term care expenditures.
- Rehabilitation is not only a healthcare issue, but also a socioeconomic issue, and has substantial implications for the working population. The great majority of disabilities have their onset during the prime adult working ages as a result of externally-imposed mechanical trauma, underlying disease and illness. Thus timely and effective rehabilitation is an important health issue that helps individuals restore function and regain the skills and abilities needed to return to life at work, at school, and at home.

C.3 THE NRH RECOMMENDS THAT A COMPREHENSIVE REHABILITATION NEEDS ASSESSMENT AND SERVICE MAPPING OF EXISTING REHABILITATION SERVICES BE UNDERTAKEN AS A VITAL COMPONENT OF THE STRATEGY

- An essential prerequisite of any strategy that includes service development is a proper objective assessment of need. Without knowing the objective need or the existing service mapping, it is difficult to plan any service development to effectively and efficiently assess how best to meet the identified need within the existing resources.
- We strongly recommend a formal needs assessment and service mapping of the existing provision of rehabilitation services be completed. Specifically, we recommend the rehabilitation service needs of persons with acquired brain injury, spinal cord and injury, progressive neurological disease, amputation and limb loss be conducted with emphasis on need throughout the life-cycle span from paediatric, adolescence, adult to geriatric.

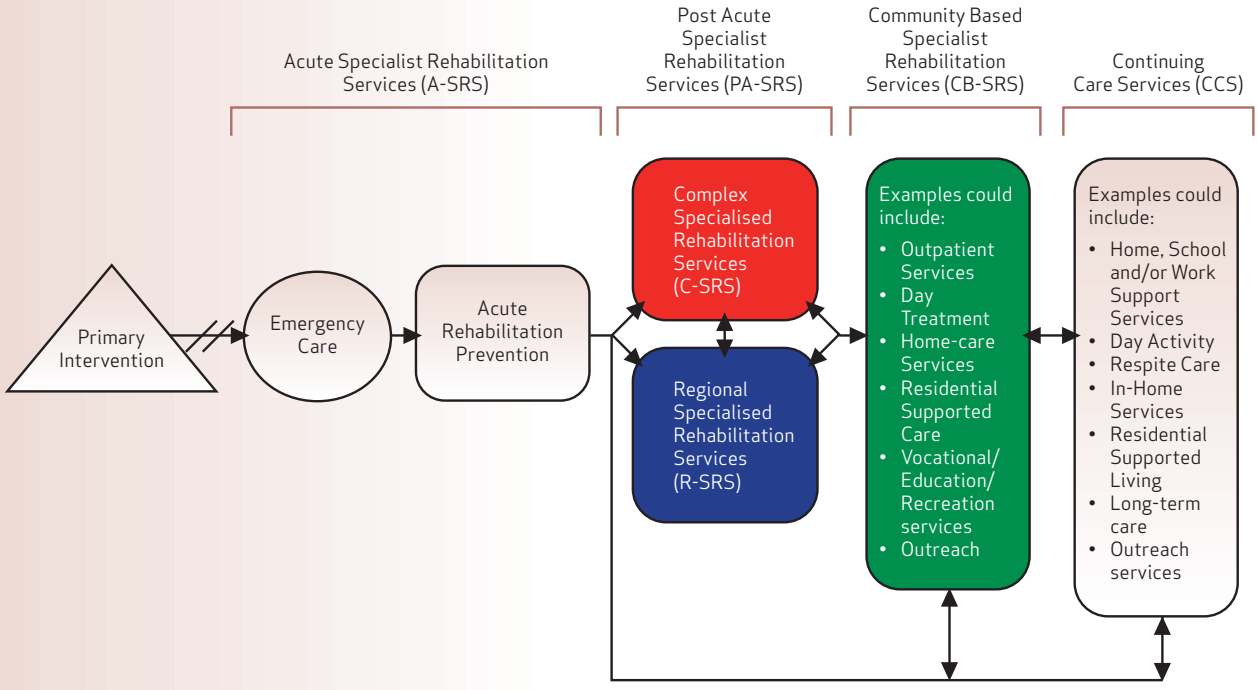
C.4 THE NRH PROPOSED MODEL SYSTEM OF REHABILITATION SERVICES

- A model system of rehabilitation care refers to the mechanism of providing a timely, coordinated continuum of care and service delivery sufficient to the needs of rehabilitation service users, from the time of onset of injury throughout the person's lifetime (Horn, 1992).
- Contemporary rehabilitation is developing new models of care in response to changing patterns of morbidity and changes in the acute care sector. These include early intervention in acute care to prevent complications and maximise function. A key feature of this work is its potential to reduce the length of stay for patients in acute care.
- The proposed *NRH Model System of Rehabilitation* Services as shown in Figure 3. includes all the components of the continuum of services delivered in a comprehensive co-ordinated system of care. The model and terminology is adapted from other published rehabilitation models of care and adapted to the Irish context (Horn 1992; Turner-Stokes 2001). The model outlines the four stages of rehabilitation services and types of services offered in each allowing patient's access to appropriate services in a fully integrated manner. Developing a fully integrated system of rehabilitation care through all stages is the challenge.
- The NRH also recommends service developments of its 4 main Rehabilitation Programmes as documented in Appendices 4-7.
- The NRH recommends seeking a national agreement on models of care that provide the early commencement of rehabilitation where appropriate, allowing rehabilitation to begin before medical stability is achieved. This should include establishing standards on the minimum number of rehabilitation beds located within an acute hospital or acute hospital campus.
- The NRH recommends seeking a national agreement to establish comprehensive ambulatory (outpatient and community) rehabilitation programs at a level that allows for rapid discharge from inpatient rehabilitation as well as for patients who require rehabilitation but do not need to receive rehabilitation on an inpatient basis.

This ***proposed NRH Model System of Rehabilitation Services*** (Figure 3) has four main integrated stages and components including:

1. Acute Specialist Rehabilitation Services (A-SRS)
2. Post Acute Specialist Rehabilitation Services (PA-SRS)
   a. Complex Specialised Rehabilitation Services (C-SRS)
   b. Regional Specialised Rehabilitation Services (R-SRS)
3. Community Based Specialist Rehabilitation Services (CB-SRS)
4. Continuing Care Services (CCS)

Figure 3: The Proposed NRH Model System of Rehabilitation Services



C.4.1 Key Components of this NRH Proposed Model System of Rehabilitation are:

i. Emphasis not only on treatment, but also primary and secondary prevention

ii. Timely to the needs of the person to maximise gain and avoid secondary impairment and disability

iii. An essential feature of the model is excellent communication and flow of information from one stage to another so that the individual can move through the stages in a "seamless continuum of care"

iv. Services must be coordinated across the healthcare continuum to ensure that persons receive the right service at the right time in a cost effective and efficient manner.

v. Services must be flexible to the person's specific individual needs

vi. Services must be local to the person served and his or her milieu to better facilitate participation of their social support network

vii. Services must recognise that different people need different input at different stages

viii. Persons may also need to access stages of services at different points in time as their needs change. This may involve re-access to inpatient services or a review of community rehabilitation and support needs as appropriate

ix. Persons progress through the different stages of rehabilitation at very different rates

x. The persons' progress through the continuum is not sequential or one directional. Persons may enter and leave the services at different points, different times, or even in reverse direction based on individual needs.

xi. The persons' progress through each stage of the rehabilitation continuum is not absolute. For example, not all people require hospitalisation, and their rehabilitation need could best be met in community services.

xii. A small minority with very severe injury may require complex specialised rehabilitation services, may spend months in hospital and may never progress to the community.

xiii. Within each stage, a range of different service providers are involved, which must somehow be coordinated

xiv. The breadth, type and complexity of rehabilitation services change according to the stage of rehabilitation.

xv. The site where this stage of rehabilitation is delivered depends on the patients' needs; for example:-

- Hospital based — if the patient requires special equipment or facilities, or the co-ordinated input of many disciplines, and can access transport to get to hospital
- Home-based — if it is important that rehabilitation is undertaken in their familiar environment. Rehabilitation in the third "community" phase must be provided flexibly in the hospital or home setting as appropriate. The availability of transport services will determine this flexibility.

C.4.2 Acute Specialist Rehabilitation Services (A-SRS)

This stage starts as soon as possible, even in the acute stages of intensive care in hospital. Interventions at this stage focus on reducing impairment and preventing secondary complications such as contractures, malnutrition, pressure sores or pneumonia, which can contribute to further morbidity and disability.

Rehabilitation is an integral component of all emergency and trauma care. Early emergency and trauma care is designed to save lives and minimise the impairment and disability associated with acute onset illness. The intensity and length of stay within acute hospital settings is largely dependent on the severity of injury.

C.4.2 Post Acute Specialist Rehabilitation Services (PA-SRS)

As the patient starts to recover, PA-SRS may be required to make the successful transition between hospital and community. PA-SRS primarily addresses regaining mobility and independence in self-care to allow the individual to return to participation in the community and manage safely at home. Interventions focus on improving activity and independence (reducing disability). PA-SRS can occur in a variety of settings including acute hospital, rehabilitation facilities and/or the community. Persons needing PA-SRS should enter as soon as possible after injury and depending upon the severity and complexity of injuries, a person would receive PA-SRS from either two categories of Regional Specialised Rehabilitation Services (R-SRS) or Complex Specialised Rehabilitation Services (C-SRS).

Persons with less severe or complex injuries could be cared for in **Regional Specialised Rehabilitation Services (R-SRS)** which are designed to restore independent function and achieve the best possible outcome through a coordinated delivery of rehabilitation services. R-SRS could occur in a variety of settings including acute hospital, rehabilitation facilities and/or the community. By their nature of service, the quantity and location of R-SRS are more likely greater and thus available on a regional basis throughout Ireland.

As defined more extensively in the preceding section, those persons with the most severe and complex injuries require admission to **Complex Specialised Rehabilitation Services (C-SRS)** with sufficient expertise and interdisciplinary rehabilitation services to achieve best outcomes. The setting of C-SRS is likely to be an inpatient acute or rehabilitation hospital. By their nature of service, the quantity and location of C-SRS are likely to be less and thus not available on a regional but on a national basis in Ireland.

Some examples of types of services in this stage in Ireland include: Acute Inpatient Rehabilitation, Day Treatment, Outpatient Services, Slow-stream Rehabilitation, Long-term Care and Outreach Services.

C.4.3 Community Based Specialist Rehabilitation Services (CB-SRS)

Once back in the community, persons requiring ongoing rehabilitation need continued input to maximise their ability to function in their environment. In CB-SRS the emphasis is usually on enhancing participation, extending functional abilities, social integration, and return to work or education. Interventions can focus on enhanced participation, improved quality of life, psychological adjustment and carer stress which may include Outpatient, Vocational and Home- care Services. Some examples of types of services in this stage in Ireland include: Outpatient Services, Day Treatment, Home-care Services, Residential Supported Care, Vocational / Educational / Recreational services and Outreach.

C.4.4 Continuing Care Services (CCS)

This stage of rehabilitation is designed to provide sustaining services in the community, school and work when persons return to independent or supported living and work in the community. Some examples of types of services in this stage in Ireland include: Home, School and/or Work Support Services, Day Activity, Respite Care, In-Home Services, Residential Supported Living, Long-term care and Outreach services.

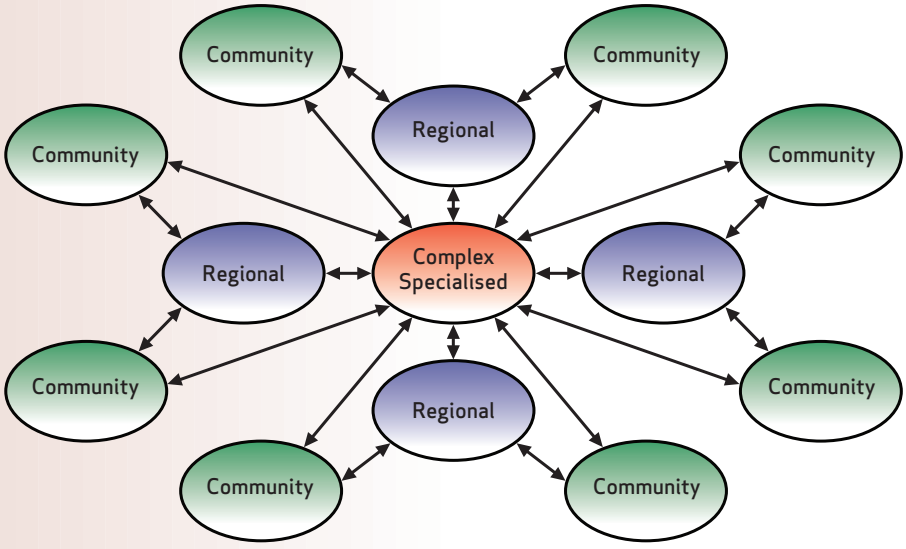
C.5 THE NRH RECOMMENDS THE DEVELOPMENT OF A COMPREHENSIVE AND INTEGRATED REGIONAL AND NATIONAL SPECIALIST REHABILITATION SERVICES NETWORK

- In the absence of a National Strategy or defined model of rehabilitation care, we have designed a strategy within our remit based on an integrated regional and national specialist rehabilitation services network.
- The NRH unequivocally supports the regional infrastructure and development of specialist rehabilitation services in Ireland but it must occur together with the development of a comprehensive, cohesive national plan which is appropriately resourced and phased to ensure that the services provided are integrated, seamless, person centred and provided as close as possible to the source of identified need.
- There is clear international evidence that effective rehabilitation can only be achieved with appropriate resourcing. The evidence is clear that higher intensity therapy improves both patient outcomes and service efficiency. Due to the lack of national standards, Ireland lags well behind most other countries on this issue. For example, in the US, it is mandatory to provide three hours of therapy per day for at least 5 days per week. Few Irish rehabilitation units, apart from the NRH, would meet the US standard.
- The NRH recommends achieving the minimum number of in-patient Rehabilitation beds with a minimum of 30 beds per 100,000 designated rehabilitation beds across adult and care of the elderly specialties. A lack of rehabilitation bed capacity results in inappropriate usage of acute care beds and delays in discharge from acute care.

- The British Society of Rehabilitation Medicine Guidelines recommends a minimum of 60 Acquired Brain Injury (ABI) in-patient rehabilitation beds per million population. Therefore there is a minimum requirement for 252 ABI beds for our population. These beds should be distributed, based on population distribution, between acute and post-acute services, and distributed in a way that reflects the critical mass of patients required to develop an expertise.
- The NRH recommends agreeing on the minimum allied health therapy levels in inpatient rehabilitation. This is recognised practice internationally and is in the order of 12 – 15 hours of therapy per week. Standards on therapy levels need to be based on the significant body of international research that demonstrates that better outcomes and efficiency are achieved with more intensive therapy.
- Rehabilitation means life-long support of those who have to live the rest of their lives with permanent disability. Not only are they prone to a variety of medical conditions, such as pressure sores, infections, contractures and other conditions, but in addition, they and their families need support to cope with the psychological, social and economic consequences of their disability. Management of chronic disability and acute rehabilitation require very different skills and services.

The NRH proposed network is based on a simple Hub and Spoke Model. This gives coordination and support for community, regional and national development of services. We propose that all rehabilitation services should be provided through a national system of four regional Rehabilitation Networks, each serving a population of about one million people (Figure 4).

Figure 4: Rehabilitation Network



- Each network would provide a range of Specialist / Specialised Rehabilitation Services across the continuum of Acute Specialist Rehabilitation Services (A-SRS), Post Acute Specialist Rehabilitation Services (PA-SRS) and Community Based Specialised Rehabilitation Services (CB-SRS).
- Each network should have a formal structure of clinical leadership, with emphasis on coordinated communication, access, information sharing and partnership leading to seamless and integrated care.
- Moreover, not all patients' needs can be met at regional level and those with complex needs must have access to appropriate national Complex Specialised Rehabilitation Services (C-SRS).
- Services should be planned in coordinated networks across a geographical area, with joint health and social services commissioning services in liaison with other statutory and voluntary agencies, including employment, education and housing authorities.
- This development should build on existing services.
- Primary care is pivotal in the coordination of the wide variety of services that patients may use. It is a key partner in the delivery of effective community and other healthcare services.
- Documents considering rehabilitation frequently ask, "Where should rehabilitation services be provided, in the hospital or in the community?" Clearly this is the wrong question. Different patients have different needs. Services need to be provided both in the hospital and in the community. The real question is "How do we make sure that individual patients can access the services that are appropriate for them?"

C.5.1 Characteristics of Specialised Rehabilitation Service networks

i. A Hub and Spoke Model of Care (Figure 5)

ii. The Hub and Spoke Model in this document refers to a concept, rather than a geographic plan set, and may be interpreted at various levels

iii. Services are provided around a central hub or specialist rehabilitation unit. This hub provides a focus for administration, staff support, training and research.

iv. Close working links are maintained with outlying parts of the service, e.g. shared or rotating staff.

v. Defined access to complex rehabilitation services in order to meet the needs of more complex cases

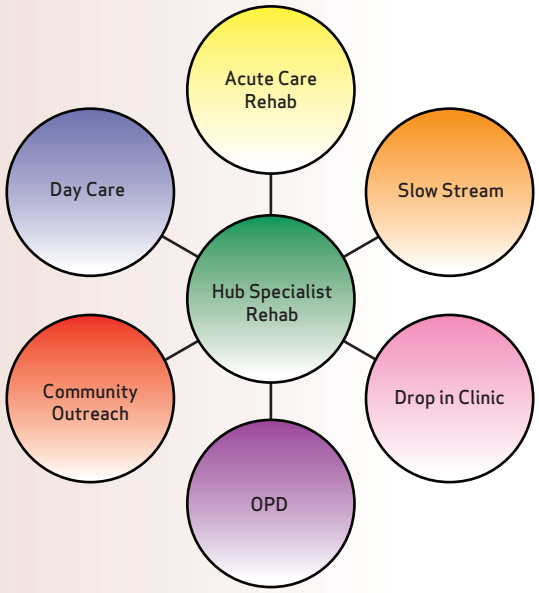
vi. Staffing and speciality levels allocated according to need

vii. Provision of training, education and guidance for other healthcare professionals involved in rehabilitation

viii. Closer working between local hospital and community rehabilitation teams

ix. Access and coordination with social services and voluntary agencies to provide continued support for the individual and their family within the home setting

Figure 5: Hub and Spoke Model



C.5.2 Advantages of the Hub and Spoke Model are:

i. Decreasing administration overhead costs by collecting several different teams together under one roof

ii. Achieving critical mass in terms of staff—optimising balance of junior to senior staff, to reduce cost of duplicating senior staff, while maintaining adequate supervision for juniors in the different teams

iii. Improved recruitment and retention—staff feel more confident and supported

iv. Development of clinical expertise as each team becomes expert in the use of techniques and procedures relevant to their own field of practice

v. Sharing of information and continuity of care between the hospital and community teams by use of common protocols and pathways

C.5.3 Barriers to the Development of Networks

i. Professional boundaries
   a. Boundaries at many levels conspire to confound effective development of co-ordinated services.

ii. Bureaucratic and Funding boundaries:
   a. Prevent patients from accessing the services most appropriate to their needs at any one time.

iii. Split between different providers
   a. The current split of services between the acute and community services leads to disjointed care and poor support for some rehabilitation professionals.
   b. Division of services into Adult and Care of the Elderly leads to inequality of service.
   c. Provision of specialist services for certain diagnostic groups can be an efficient way to deliver care, but provision must be made for patients who do not fit into any of the specialist categories.

iv. Split between health and social services
   a. Different areas have different arrangements for sharing the responsibility of continuing care and rehabilitation between health and social services. Much time and effort is wasted in arguing over who is responsible for which part of an individual patient's care.

v. Lack of understanding of exactly what specialist rehabilitation is;
   a. Resources are tight, but are particularly so in this less-well publicised area of care which fails to compete with the pressures on the acute services.

vi. Increasing demand
   a. Improved acute care such as helicopter evacuation from accidents, and medical/surgical advances mean that more patients survive with severe disability. This trend is likely to continue and we need to plan for greater demand on rehabilitation services, not only in terms of numbers, but also in terms of greater complexity and dependency on care.

vii. Lack of suitably trained rehabilitation professionals
   a. Around the country there are a small number of specialist rehabilitation services providing high quality care and services, but these are insufficient to cope with the number of patients requiring them and their expertise is not used to maximum efficiency.

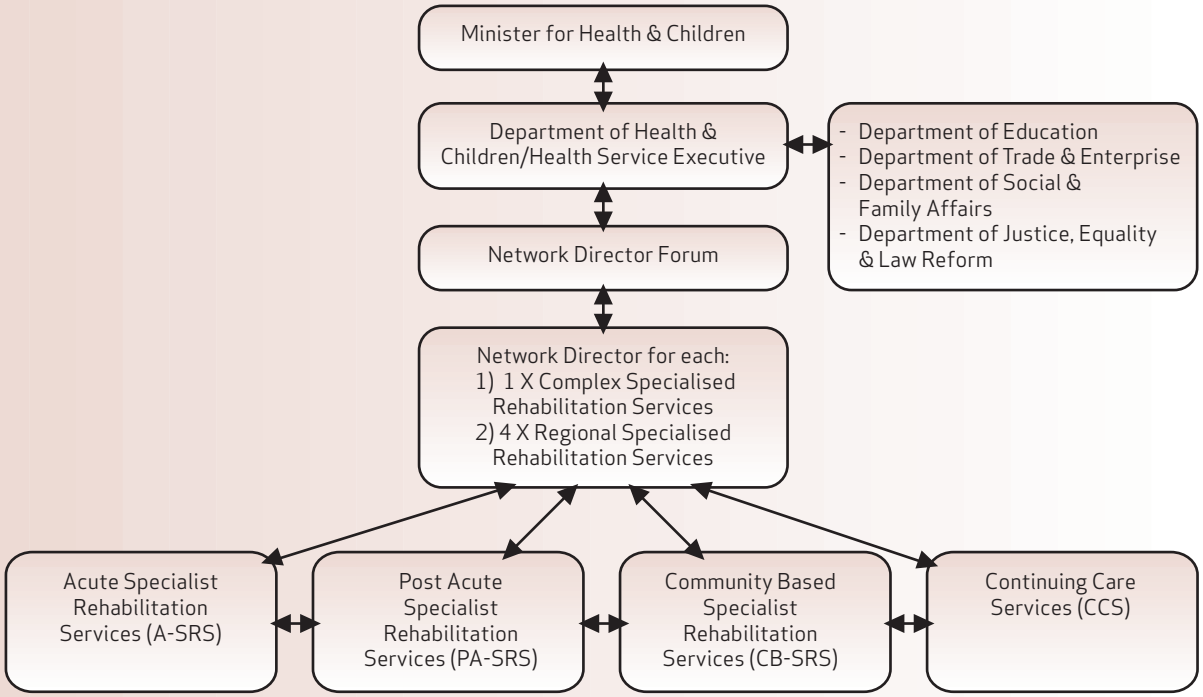
C.6 THE NRH RECOMMENDS THE NEED FOR COMMUNITY BASED SPECIALIST REHABILITATION SERVICES (CB-SRS) AND CONTINUING CARE SERVICES (CCS) DEVELOPMENT

- Community based rehabilitation services must be developed to augment hospital services and to ensure that the acute /post acute rehabilitation facility does not become blocked and become a chronic service – thus defeating the purpose of establishing an acute/post acute unit.
- The current focus of Irish government funded community care is on maintenance and support (non-acute) services and much less supportive of rehabilitation and other continuing care. This is despite international evidence that two thirds of people seeking community care are often assessed as having the potential for increased independence. This significant group do not receive rehabilitation. Instead, they receive maintenance care. The end result is a long-term burden for them, their family and the health system.
- There needs to be access to funding that follows the individual across the continuum of care to allow appropriate access to rehabilitation in order to maximise potential for the individual and reduce dependency.
- Community support and networks must be developed to ensure that rehabilitation and community support services are available and accessible for patients on discharge from hospital.

C.7 THE NRH PROPOSED MANAGEMENT STRUCTURE FOR A COMPREHENSIVE AND INTEGRATED REGIONAL AND NATIONAL SPECIALISED REHABILITATION SERVICES NETWORK

- No one in the Irish Healthcare system has clear responsibility for rehabilitation policy, planning, service provision or workforce development. For example, there is no section in the Department of Health and Children that has responsibility for rehabilitation. The outcome of this deficiency is that the potential contribution of rehabilitation towards improving the efficiency of acute care has been reduced.
- We propose a possible management and reporting structure of a 4 regional rehabilitation services network as outlined in Figure 6.

Figure 6: NRH proposed Management and Reporting Structure for a Rehabilitation Services Network



C.8 THE NRH RECOMMENDS THE APPOINTMENT OF AN INTERNATIONAL INDEPENDENT EXPERT TO ASSIST IN THE DEVELOPMENT OF A REHABILITATION STRATEGY

- The NRH recommends that it would be appropriate for the Working Group/Steering Group to seek input from an independent international expert in the field of Rehabilitation. Recommendations on the best strategy for national and regional development will depend on robust analysis of the current evidence- base.

C.9 THE NRH RECOMMENDS IMPLEMENTATION OF A QUALITY AND ACCREDITATION FRAMEWORK FOR REHABILITATION

- A vital part of developing rehabilitation services in Ireland is to ensure that any individual receiving any form of rehabilitation service in any part of the country receives services comparable with the highest possible, evidence-based standards supported and bench-marked with best practice internationally and adapted within the Irish context.
- To accomplish this goal we recommend the creation of a National Framework for Quality and Accreditation for all rehabilitation service providers that would lead to the development of standards, guidelines and continuous accreditation mechanisms for the delivery of rehabilitation services in Ireland.
- HIQA should establish a national multidisciplinary group charged with the responsibility to develop and implement this goal.

C.10 THE NRH RECOMMENDS THE DEVELOPMENT OF A NATIONAL REHABILITATION SERVICES WORKFORCE PLAN

- Like other parts of the healthcare sector, this sector is facing shortages of trained rehabilitation-specific healthcare professionals and specialists. This includes all disciplines including medicine, nursing and rehabilitation specialists (e.g. physiotherapy, occupational therapy, speech therapy, dietician, psychology and social workers).
- We recommend that the HSE develop a National Rehabilitation Services Workforce Plan to ensure that there are adequate levels of highly skilled rehabilitation staff across all rehabilitation related disciplines.

C.11 THE NRH RECOMMENDS INVESTMENT IN EDUCATION AND RESEARCH INTO REHABILITATION

- Rehabilitation education and research are essential components in the development, implementation and evaluation of a national rehabilitation services programme.
- Recent advancements in rehabilitation specific scientific knowledge and research has led to the development and availability of new medical treatments for many disabling injuries and diseases (e.g. brain and spinal injury, multiple sclerosis) that have contributed to longer lifespans and, at the same time, placed an increased demand on the need for rehabilitation and community services that help individuals manage, maintain and/or improve their functional abilities as people age. In addition, research is also leading to new understandings of factors that contribute to peoples' success in regaining functional independence, to their fullest potential, following trauma or illness. It is vital that service delivery of rehabilitation keeps up to date with current research in order to implement best practice.
- New treatments are frequently costly and national guidance is needed on the evidence basis for their use and potential. A national agency capable of benchmarking new treatments and equipment would be of considerable benefit.
- There needs to be promotion and development of a wide-ranging research programme that encompasses all fields of clinical and service delivery rehabilitation research

C.12 THE NRH RECOMMENDS THE DEVELOPMENT OF COORDINATED DATA COLLECTION SYSTEMS SPECIFIC TO REHABILITATION

- There is a lack of information about rehabilitation collected through national and state data collections, with only very basic indicators included in the Census, the National Disability Database and through HIPE. Furthermore, no one seems to know what to do with the limited data that is collected.
- There is a marked absence of coordinated and specific data from the rehabilitation sector including utilisation, performance and outcomes.
- Reliable data reflecting utilisation, performance and outcomes of rehabilitation services is either non-existent or difficult to obtain. Complicating the problem is the fact that various rehabilitation service providers do not use the same indicators in order to collect this information uniformly.
- Furthermore, in spite of the growth and costs related to disabling conditions across the country and the corresponding need for "value for money", the use of research in proving the effectiveness and efficiency of rehabilitation services in Ireland is limited.
- The HSE should develop a system of data collection through a process that involves the examination of international approaches to cover the major areas of rehabilitation.

Call for Submissions on a Policy/Strategy for Rehabilitation Services

The Department of Health and Children and the Health Service Executive are developing a National Policy/Strategy for the Provision of Rehabilitation Services. A Working Group has been established which includes key stakeholders and experts to assist with this process.

The Terms of Reference of the Working Group are:

"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 and
- Other physically disabling conditions who may benefit from medical, psychological and/or social rehabilitation service provision."

The objectives of this process are the development of:

- An appropriate policy framework
- A strategy for service provision and
- A preferred model of care.

A report will be prepared for submission to the Secretary General of the Department of Health and Children and the CEO of the Health Service Executive.

To assist and inform the Working Group to deliver on its task, we are inviting submissions from organisations and individuals in relation to the above Terms of Reference.

Written submissions should be forwarded:

By e-mail to:
rehabilitationconsultation@health.gov.ie

By post to:

Strategy for Rehabilitation Services Consultation
Room 6.29
Office for Disability and Mental Health
Department of Health and Children
Hawkins House
Dublin 2

Appendix

Listing of NRH links and affiliations with other Organisations and Rehabilitation Providers

Action for Disability

Acute Hospitals and Regional Hospitals throughout Ireland

An Bord Altranais – Irish Nursing Board

Association of Hospital Chief Executives

Association of Occupational Therapists Ireland

Bariatric advisor at St. Colmcilles' Hospital

BRÍ

British Association of Rehabilitation Medicine

British Dietetic Association – BDA

British Society of Prosthetics and Orthotics

Cappagh National Orthopaedic Hospital

Central Remedial Clinic (CRC)

Chartered Institute for Personnel Development – CIPD

Department of Finance – (Disabled Drivers Medical Board of Appeal)

Department of Health and Children

Dublin Hospitals Group Health and Safety Forum

Dublin Hospitals Group Insurance Scheme

Dublin Hospitals Group Risk Management Forum

Dublin Institute of Technology (DTI)

Enable Ireland

European Federation of Physical Medicine and Rehabilitation

FARM – Forum for Academics in Rehabilitation Medicine

Headway

Health Service Executive

Health Service Executive Employers Agency

Hospital Procurement Services Group (HPSG)

HSE Physical and Sensory Disability Forum

Institute of Directors of Ireland

International Society for Augmentative and Alternative Communication

International Society of Prosthetics and Orthotics

Irish Association of Directors of Nursing and Midwifery – IADNAM

Irish Association of Neurologists

Irish Association of Rehabilitation Medicine

Irish Association of Social Workers

Irish Association of Speech and Language Therapists

Irish Business Employers Confederation (IBEC) Voluntary Hospital's Group

Irish Committee on Higher Medical Training

Irish Gerontological Society

Irish Healthcare Risk Management Association

Irish Heart Foundation

Irish Medical Organisation

Irish Nursing Organisation

Irish Nutrition and Dietetics Institute – INDI

Irish Society of Chartered Physiotherapists

Irish Wheelchair Association

Joint United Kingdom Physiotherapy Clinical Leads in Spinal Cord Injury

Mercy Group Hospitals Committee

NRH / Beaumont Hospital Brain Injury Unit Project Team

Opcare (Prosthetic and Orthotic Strategic Partner of NRH)

Orthopaedic Hospital, Clontarf

Peter Bradley Foundation

POBAL

Psychological Society of Ireland

Radiation Safety HSE Taskforce

Radiological Protection Advisors at SVUH and St. James' Hospital

Royal College of Physicians of Ireland

Royal College of Speech and Language Therapy

Spinal Injuries Ireland

Stroke Foundation Ireland

TCD Children's Research Group

The Spinal Cord Injury Vocational Programme (NRH, SII, HSE & FAS)

Therapy Grades Group (Department of Health and Children)

Trinity College, Dublin (TCD)

Try-it-ie (Assistive Technology Loan Bank)

University College Galway

University College, Dublin (UCD)

University of Limerick

Volunteer Stroke Scheme

World Federation of Rehabilitation Medicine

Register of Research in Progress and Completed at NRH

Research Project	Principal Investigator	Co-Investigator	Researcher	Duration of Research
Music Therapists' Strategies in Implementing New Posts within Health Care Settings	Dr. Hugh Monaghan, Consultant Neuro-paediatrician	Professor Jane Edwards, University of Limerick	Ms. Alison Ledger, Health Research Board Fellow, UL	November 2008 -
Differences in Marital Satisfaction, Coping and Social Support following a Traumatic Brain Injury	Dr. Áine Carroll Consultant in Rehabilitation Medicine, NRH	Ms. Patricia Byrne, Clinical Neuropsychologist, NRH	Ms. Anne Marie Casey, Assistant Psychologist, NRH	November 2008 -
Cognitive impairments in traumatic brain injury novel biomarkers for new treatments	Dr. Mark Delargy Consultant in Rehabilitation Medicine, NRH	Dr. Paul Dockree, Institute of Neuroscience, TCD	Dr. Paul Dockree, Institute of Neuroscience, TCD	March 2008 -
Optimising the prescription of prosthetic technologies (opptec): Outcome measures for evidence based prosthetic practice and use	Dr. Nicola Ryall Consultant in Rehabilitation Medicine, NRH	Dr. Pamela Gallagher, DCU Ms. Sinead Ni Mhurchadha, DCU Ms. Elisabeth Schaffalitzky, DCU	Ms. Sinead Ni Mhurchadha, School of Nursing, DCU Ms. Elisabeth Schaffalitzky, School of Nursing,DCU	November 2007 -
An exploration of Peri and Post Partum Stroke in the context of Relationships of the Individuals Affected	Dr. Áine Carroll Consultant in Rehabilitation Medicine, NRH	Ms, Patricia Byrne, NRH Ms. Áine Finan, Dept. Psychology, TCD	Ms. Áine Finan, Dept. Psychology, TCD	November 2007 -
National Drug-Related Deaths Index	Dr. Jacinta Morgan Consultant in Rehabilitation Medicine, NRH	Ms. Suzi Lyons, Senior Research Officer, Health Research Board Ms. Ena Lynn, Research Officer, Health Research Board	Ms. Ena Lynn, Research Officer, Health Research Board	July 2007 -
An exploration of child and adolescent sibling's experience of paediatric traumatic brain injury	Dr. Hugh Monaghan Consultant in Neuro Paediatric Rehabilitation Medicine, NRH	Dr. Sarah O'Doherty, NRH Ms. Heather Cronin, Dept Psychology, TCD	Ms. Heather Cronin, Dept. Psychology, TCD	July 2007 -
Rehabilitation of Awareness of deficits in Patients with Traumatic Brain Injury Applying a User-Friendly Computerised Intervention Approach	Dr. Jacinta Morgan Consultant in Rehabilitation Medicine, NRH	Dr Simone Carton, NRH Ms. Mary Fitzgerald, Department of Clinical Neuropsychology, NRH	Ms. Mary Fitzgerald, Department of Clinical Neuropsychology, NRH	May 2007 -

APPENDIX 3 **REGISTER OF RESEARCH IN PROGRESS AND COMPLETED AT NRH**

Research Project	Principal Investigator	Co-Investigator	Researcher	Duration of Research
A Generic Electronic Assisted Technology (EAT) package for Persons with Quadriplegia	Dr. Jacinta McElligott Consultant in Rehabilitation Medicine, NRH	Michele Verdonck, Senior Occupational Therapist, NRH	Michele Verdonck, Senior Occupational Therapist, NRH	January 2007 -
Prospective Memory Deficit Following Traumatic Brain Injury: Level of Awareness, rate of Recovery and Psychosocial Outcome	Dr. Mark Delargy Consultant in Rehabilitation Medicine, NRH	Dr. Simone Carton, NRH Ms. Melanie Clune, Dept. Psychology, UCD	Ms. Melanie Clune, Dept. Psychology, UCD	November 2006 -
Longitudinal Investigation of Cognitive Appraisals, Coping and Psychological Outcomes: A Multicentre European Study	Dr. Angela McNamara / Dr. Jacinta McElligott Consultant in Rehabilitation Medicine, NRH	Dr. Simone Carton, NRH Ms. Maeve Nolan, Department of Clinical Neuropsychology, NRH	Ms. Maeve Nolan, Department of Clinical Neuropsychology, NRH	January 2007 -
The Prevalence of Osteoporosis in the Disabled Population at the National Rehabilitation Hospital	Dr. Áine Carroll Consultant in Rehabilitation Medicine, NRH	Dr. Éimear Smith, Specialist Registrar in Rehabilitation Medicine, NRH	Dr. Éimear Smith, Specialist Registrar in Rehabilitation Medicine, NRH	January 2006 -
Standards of Practice in Irish and UK Hydrotherapy Pools	Dr. Angela McNamara Consultant in Rehabilitation Medicine, NRH	Ms. Aoife Langton Senior Hydrotherapist, NRH	Ms. Aoife Langton Senior Hydrotherapist, NRH	Completed 2008
Assessing the impact of previous experience, and attitudes towards technology, on levels of engagement in a virtual reality based occupational therapy intervention for spinal cord injury rehabilitation	Dr. Manus McCaughey Consultant in Rehabilitation Medicine, NRH	Mr. Paul O'Raw, School of Psychology, UCD	Mr. Paul O'Raw, School of Psychology, UCD	Completed 2007
Evaluation of a Coping Effectiveness Training Programme in a Spinal Cord Injured Population	Dr. Angela McNamara Consultant in Rehabilitation Medicine, NRH	Ms. Suzanne Meenan, Department of Clinical Neuropsychology, NRH	Ms. Suzanne Meenan, Department of Clinical Neuropsychology, NRH	Completed 2007
Self Awareness after Brain Injury: emotional distress and executive functioning	Dr. Mark Delargy Consultant in Rehabilitation Medicine, NRH	Ms. Judith McBrinn, Psychologist in Clinical Training, NUI Galway	Ms. Judith McBrinn, Psychologist in Clinical Training, NUI Galway	Completed 2007
An evaluation of virtual reality technology as an occupational therapy treatment tool in spinal cord injury rehabilitation	Dr. Angela McNamara Consultant in Rehabilitation Medicine, NRH	Mr. Paul O'Raw, School of Psychology, UCD / Michele Verdonck, Senior Occupational Therapist, NRH	Mr. Paul O'Raw, School of Psychology, UCD	Completed 2006
Assessment of Perceived Stress amongst Nursing Staff in a Rehabilitation Hospital	Dr. Jacintha More O'Fearall, Occupational Health Physician, NRH	Ms. Rose Curtis Occupational Health Nurse, NRH	Ms. Rose Curtis Occupational Health Nurse, NRH	Completed 2006
Awareness and Sustained Attention following Traumatic Brain Injury	Dr. Mark Delargy Consultant in Rehabilitation Medicine, NRH	Dr. Simone Carton, NRH Prof. Ian Robertson, TCD Dr. Paul Dockree, TCD	Dr. Paul Dockree Dr. Simone Carton	Completed 2005

APPENDIX 3 **REGISTER OF RESEARCH IN PROGRESS AND COMPLETED AT NRH**

Research Project	Principal Investigator	Co-Investigator	Researcher	Duration of Research
An Investigation into the functional independence of individuals with Spinal Cord Injury following discharge.	Dr. Angela McNamara Consultant in Rehabilitation Medicine, NRH	Ms. Lisa Held, BScOT, NRH	Ms. Lisa Held, BScOT, NRH	Completed 2005
The Reliability of the Community Outing Performance Appraisal (COPA) to assess the abilities of Adults with Acquired Brain Injury	Dr. Mark Delargy Consultant in Rehabilitation Medicine, NRH	Ms. Fiona Ryan, BScOT, NRH	Ms. Fiona Ryan, BScOT NRH	Completed 2005
An investigation into the occupational status of persons with incomplete Spinal Cord Injury	Dr. Angela McNamara Consultant in Rehabilitation Medicine, NRH	Ms. Catherine Logan, Senior OT, NRH	Ms. Catherine Logan, Senior OT, NRH	Completed 2005
Strategies for Crisis Intervention & Prevention (SCIP): Does it work?	Dr. Simone Carton Head of Clinical Psychology, NRH	Mr. Ray Messitt, Nursing Dept, NRH	Mr. Ray Messitt, Nursing Dept, NRH	Completed 2005
Assessment of Financial Competency in Patients with Acquired Brain Injury	Dr. Mark Delargy Consultant in Rehabilitation Medicine, NRH	Dr. Simone Carton, NRH Mr. Nick Kidd, Dept. Psychology, TCD	Mr. Nick Kidd, Dept. Psychology, TCD	Completed 2005
A Pilot Study of the Safety and Effectiveness of the Traxon Spinal Cord Repair Stimulator for the Treatment of Complete Spinal Cord Injury in Humans	Dr. Patrick C Murray, Consultant in Rehabilitation Medicine, NRH	Professor Ciaran Bolger, Consultant Neurosurgeon, Beaumont Hospital	Ms. Linda McEvoy	Completed 2004
Psychological Aspects of Amputation: A cross-Sectional Study	Dr. Nicola Ryall, Consultant in Rehabilitation Medicine, NRH	Prof. Malcolm MacLachlan Department of Psychology, Trinity College Dublin	Ms. Olga Horgan	Completed 2004
Traumatic Brain Injury and Subsequent Rehabilitation – Focussing on the Future	Dr. Mark Delargy Consultant in Rehabilitation Medicine, NRH	Prof. J.P. Phillips/ Dr. Lourda Geoghegan Dept. of Public Health Medicine, UCD	Dr. Lourda Geoghegan	Completed 2004
Nurses' Perceptions of their Role as part of the Multi-professional Team in an Acute Rehabilitation Setting			Ms. Fanchea McCourt Education Co-ordinator, NRH	Completed 2004
Evaluation of Service Needs and Provisions in Relation to Children and Young People with Acquired Brain Injury in Ireland	Dr. Hugh Monaghan, Consultant Neuro-Paediatrician, NRH	Dr. Diane Hogan The Children's Research Centre, TCD	Dr. Caroline Heary Dr. Diane Hogan	Completed 2003
Parents' Perspectives on reintegration of Students with Acquired Brain Injury into the Irish School System			Ms. Mary O'Connor School Principal, NRH	Completed 2002

4

Appendix

Brain Injury Programme at NRH

Traumatic Brain Injury (TBI) remains the leading cause of death and disability in young individuals and the leading cause of TBI in young individuals is road traffic accidents. TBI is a significant contributor to morbidity and mortality at all stages of life.

There are no reliable incidence estimates for Acquired Brain Injury (ABI) in Ireland. A useful estimate, for Ireland, can be reached by extrapolating from the Thornhill et al, paper from Glasgow (BMJ 2000). The extrapolated incidence of TBI survivors needing rehabilitation in Ireland is currently in the range 4,600 – 6,300 / annum. TBI resource planning should provide rehabilitation resources based on the incidence range of 100 - 150/100,000 population /year. While the Glasgow paper provides an incidence range benchmark for TBI, ABI, however, includes those with non traumatic brain injury eg Stroke, Sub-arachnoid Hemorrhage (SAH), Encephalitis and benign tumours. The BSRM have estimated the ABI incidence at 275/100,000 which correlates with an ABI incidence of 10,550/annum in Ireland.

The rehabilitation resources available nationally must be sufficiently numerous and diversely skilled to address the ABI incidence. The RCS(E) Working Party report on head Injuries(1999) has recommended that people with intermediate and severe head injuries should be transferred directly to a multidisciplinary rehabilitation unit and not to acute surgical or medical wards, as still happens in Ireland some 10 years after the RCS(E) report.

The BSRM report on ABI (2003) serves as a guide for the number of beds needed in Ireland for ABI rehabilitation. The BSRM report estimates the number of specialist ABI rehabilitation beds at 60 beds/million population. Based on the current population estimate, Ireland needs 255 TBI rehabilitation beds. The NRH is the only specialist rehabilitation provider for inpatient ABI in Ireland and currently provides 46 specialised ABI beds. The planned increase in ABI beds to 150, as part of the new NRH development, will be a significant step forward in meeting the national bed requirement. Regional rehabilitation bed development is also needed to complete predicted rehabilitation bed requirements.

The BSRM have further estimated that 25/100,000 have moderate to severe brain injury. In Ireland, this extrapolates to just over 1000 people with brain injury who are likely to need intensive, prolonged multidisciplinary rehabilitation. Based on planned capacity of 150 beds in the new NRH and an average 12 week inpatient NRH rehabilitation stay, the new NRH (with 4 bed turnovers /year) will be able to serve the initial rehabilitation needs of 600 moderate to severe ABI survivors/year.

The resources required to reduce the inpatient stay to, say 8 weeks, would require a major increase in staffing, to bring the NRH capacity to 800/annum. (Extra capacity would still be needed for readmissions and people with mild ABI.) In any case substantial regional rehabilitation development will be needed for approximately 200 – 400 moderate to severe ABI survivors/year.

Rehabilitation in the Model System of Care

The model referred to below is based on a US model system of care – this model can be easily adapted to the Irish context, and using the model as illustrated in the NRH proposed Model System of Rehabilitation Service (see figure 3), the seamless timely and efficient movement of patients through the system can be achieved.

The continuum of care for individuals with TBI occurs in a variety of settings across the healthcare system. Within the continuum, people with TBI flow in and out through the rehabilitation system at different points and at different times depending on needs and service availability. (Brain Injury, Katz, Zasler, Zafonte Chapter 1. Clinical continuum of care and natural history)

The key component of ABI service delivery is the "continuum" of care from injury prevention to early intervention and trauma care, acute hospital ICU care and secondary prevention, acute inpatient rehabilitation services and post acute rehabilitation services, subacute and continuing care services, through to outpatients and vocational rehabilitation services. In addition home and community based services, and residential rehabilitation services are all essential components of the continuum of care for ABI. Developing a fully integrated system of care from acute hospital, inpatient rehabilitation to continuity of community services has been a challenge for ABI worldwide.

A "spectrum" of services across the healthcare continuum is essential to ensure that individuals receive the right service at the right time delivering best outcome by utilising the most appropriate resources in a cost effective, cost efficient manner.

The "model" system of care for TBI includes all the components of the spectrum of services delivered in a comprehensive co-ordinated system of care. As is the case for Stroke Unit care, best results are achieved when services are delivered by integrated multidisciplinary teams.

There are 13 Model Systems of care funded through the National Institute of Disability Research in the US. These centres were designed to implement best practice and research outcomes through coordinated delivery of rehabilitation services. These model systems for TBI are based on the successful implementation of Model Systems of care for Spinal Cord Injury (SCI) which has had proven success in improving survival, longevity, reducing morbidity, and improving outcome and quality of life for individuals with spinal cord injury.

Four integrated phases are described in the rehabilitation "Model" system of care.

The US model systems are generally considered to be a well organised comprehensive integrated system of care and inform service development in Ireland.

Management of TBI is as follows:

1. Acute Medical/Surgical Phase

The acute medical/surgical phase includes primary prevention, emergency care and acute care rehabilitation and secondary prevention. This phase is most effectively delivered in a coordinated system of trauma care. (Trauma system development in North America. Hoff William, Schwab C William, Clinical Orthopaedics, and Related Research. Vol. 422, May 2004, pp17-22). These emergency and immediate care services are based in acute hospitals. Rehabilitation is an integral component of all trauma care and comprehensive rehabilitation teams are needed in every acute hospital which receives accident and emergency patients. Early emergency and trauma care is designed to save lives and minimise the impairment and disability associated with TBI. The intensity and length of stay within acute hospital settings is largely dependent on the severity of injury.

Rehabilitation in acute hospital setting is designed to prevent secondary complications which can contribute to morbidity, disability, and length of stay. Rehabilitation in acute hospital settings should be on average less than 6 weeks for those patients with severe injuries. (As per the HSE/Beaumont/ NRH recommendations for the NRH@Beaumont unit)

2. Acute Rehabilitation Phase.

Once the patient is clinically stable he/she should be transferred from the acute hospital setting and enter the acute rehabilitation phase which is designed to restore independent function and achieve the best possible outcome through a coordinated delivery rehabilitation services. The specialised rehabilitation phase includes rehabilitation services delivered through acute inpatient rehabilitation brain injury programmes, coma programmes, continuing care facilities, and outpatient and day treatment services.

People with the most severe injuries require admission to an acute inpatient rehabilitation programme with sufficient interdisciplinary rehabilitation services to achieve best outcomes including return to community independent living and work, where possible. The intensity of services and length of stay in acute inpatient rehabilitation programmes depends largely on the severity and complexity of injury. Early rehabilitation is associated with improved outcomes. Patients should enter the acute medical rehabilitation phase as soon as possible after injury (1-6 weeks) with a length of stay in acute inpatient rehabilitation of up to12 weeks depending on severity of injury. After very severe ABI inpatient stay combined acute and rehabilitation, phases can run to many months while those in PVS will need specialised long term care.

Those with less severe injuries can be supported by high capacity, comprehensive, and timely outpatient, day treatment, or individual community services. Based on the standard classification of acute ABI using the GCS system which separates ABI into mild, moderate and severe it might be expected that people with mild TBI need little rehabilitation services. Counter intuitively, as many as 48% of those in the mild category need substantial rehabilitation services. (Ref. Thornhill et al)

The majority of people with TBI eventually return to independent or supported community living. A small percentage of patients require long term home care or care in a continuing care setting.

3. Post Acute Rehabilitation Phase

The post acute rehabilitation phase is designed to provide community integrated rehabilitation services which may include outpatient, vocational and home care services.

4. Supported Adapted Lifestyle Phase

The supported adapted lifestyle phase of rehabilitation is designed to provide sustaining services in the community, school and work when individuals with TBI return to independent or supported living and work in the community. The majority of people make significant recovery especially in the first 6 months post injury. In some, further adaptation may be possible with focused phases of rehabilitation intervention for many years after injury. People with ABI should be assisted in achieving return to stable adapted lifestyle as soon as possible after injury. Even those people with the most severe injuries should have achieved a stable adapted lifestyle by one year. However, they may need to re-enter services or be able to continue to benefit from vocational and community based services.

SERVICES PROVIDED – BRAIN INJURY PROGRAMME AND COMPREHENSIVE INTEGRATED INPATIENT REHABILITATION PROGRAMME (CIIRP)

Following appropriate referral to the Brain Injury or CIIRP Programme at NRH, the person will receive a preadmission assessment to identify their unique medical, physical, cognitive, communicative, psychosocial, behavioural, vocational, educational, cultural, family, spiritual and leisure/recreational needs. This is also an opportunity for persons referred to receive information about the Brain Injury Programme including characteristics of persons served, types of services offered, outcomes and satisfaction of previous patients, and other relevant information. Following this assessment and, if the person meets the admission criteria, they may be offered admission to the BI or CIIRP Programme.

Following admission the interdisciplinary team members, in collaboration with the patient and their family/support network, will develop a comprehensive treatment plan that addresses the identified needs of the patient and their family/support network. Patients and their family/support network are offered appropriate information and opportunity for feedback at every stage of the rehabilitation process, and are actively involved in decisions regarding their care. Patients and their family/support network are also offered education regarding primary prevention of further ABI and secondary prevention related to better management of potential risks and complications.

People admitted to the BI or CIIRP Programme receive a minimum of two hours of direct services per day, Monday to Friday. Direct service intensity differs on weekends depending on resources available and individual needs, and to facilitate home or community leave for gradual reintegration of the person into these environments.

Types of services offered in the Brain Injury/CIIRP Programme to meet identified needs could include:

- Activities of Daily Living assessment and management
- Adaptive equipment assessment and training
- Assistive technology assessment and training
- Audiology screening
- Behavioural assessment and management
- Bowel and bladder retraining
- Chiropody
- Clinical neuropsychological assessment and psychotherapy
- Cognitive retraining
- Communication assessment and management
- Coping and adjustment to disability
- Dental Services
- Dysphagia assessment and management
- Family/ carer training and education
- Hydrotherapy
- Independent living assessment & training
- Medical assessment and management
- Mobility assessment and management
- Nutritional counselling and management
- Orthopaedic assessment
- Orthotics and splinting
- Pastoral and spiritual services
- Patient advocacy service
- Patient and family support counselling
- Pharmacological management
- Pre-driving and community transport assessments
- Prosthetic services
- Radiology
- Rehabilitation nursing
- Respiratory therapy
- Safety awareness and training
- Sexual counselling
- Urology service
- Vocational assessment and counselling

If additional services are required and not available on site, the programme facilitates referral to certain ancillary services.

Examples of these ancillary services could include:

- Advanced assistive technology assessment and prescription
- Fiberoptic endoscopic examination of swallowing
- Medical speciality consulting including Psychiatry , Radiology-Brain Imaging, Neuro-ophthalmology, Neuro-psychiatry and Orthopaedics
- On-road driving assessment and training
- Optician
- Osteoporosis assessment
- Podiatry
- Substance abuse counselling
- Video fluoroscopic swallowing evaluation

People with ABI frequently have complex disabilities and needs which require specialist intervention by professionals with knowledge and experience in the management of brain injury. The composition of the interdisciplinary team for each person served is determined by the assessment of the person's individual medical and rehabilitation needs. These team members could include:

- Brain injury liaison nurse
- Chaplain
- Clinical Neuropyschologist
- Clinical psychologist
- Dietitian
- Discharge liaison occupational therapist
- Dysphagia therapist
- Health care assistants
- Medical Social worker
- Occupational therapist
- Pharmacist
- Physiotherapist
- Rehabilitation medicine specialist
- Rehabilitation nurse
- Speech and language therapist
- Sports therapist

Services Provided for Families and Carers

Families and carers are partners in the rehabilitation process and are encouraged to participate in all phases of the programme. Information, counselling, emotional and psychological support can reduce the emotional sequelae experienced by the family/carer. This support may help them to adapt and come to terms with life changes, and so result in better long-term outcomes for both the patient and the family. Rehabilitation is a continuous and life long process. The carrying over of new skills gained in treatment into daily activities and into discharge environments is critical to the success of any rehabilitation programme.

Many services are available within the Brain Injury Programme at NRH to meet the needs of the patients' family/carers including:

- Education/training about management of ABI related issues (e.g. NRH Stroke Awareness for Carers programme, printed resource material, informal instruction and practical skills training in preparation for discharge).
- Psychological support services
- Pastoral and spiritual services
- Peer support through interaction with other families and various community support groups (e.g. Brí, Peter Bradley Foundation and Headway Ireland).
- Information about community support, advocacy, accommodation and assistive technology resources.
- Trial of supported living on site in our short stay independent living facility.

National Rehabilitation Hospital ABI Service components.

- The NRH is the only post acute inpatient rehabilitation programme for individuals with TBI in Ireland. Referrals are received nationwide from all the acute hospitals and HSE service areas. In response to referral demand, the NRH has expanded its capacity to 46 beds for the Brain Injury Rehabilitation Programme. The NRH ABI programme spans the continuum of care from acute hospitals to inpatient rehabilitation, OPD and community based services. The NRH has 4 rehabilitation consultants specialising in the provision of services for people with ABI. Each rehabilitation consultant has the majority of their sessions at NRH with other sessional commitments to the acute hospitals at Beaumont, AMNCH, SVUH, and the Mater Hospital. Each ABI rehabilitation consultant receives referrals from and coordinates services for patients from a specific HSE area and utilises designated brain injury beds and OPD resources for the HSE service area under their jurisdiction. Referrals mainly come from acute hospitals but also from discharge services in the HSE PCCC community based services.
- The NRH provides Brain Injury liaison services, pre and post inpatient rehabilitation. The NRH provides follow up as required for patients with severe brain injury. Life long follow up for severe TBI would be desirable as is the norm in the SCI system.
- Specialised spasticity management and a neurobehavioural clinic are important components of inpatient and OPD services. The NRH provides comprehensive OPD services, vocational and driving assessments.

- The Rehabilitative Training Unit provides a residential vocational rehabilitative training programme.
- The NRH provides a coordinated interdisciplinary acute inpatient rehabilitation programme for patients with TBI. The NRH inpatient rehabilitation programme spans the continuum of care from preadmission consultations in the acute hospital to post acute services, discharge and long term follow up.
- The NRH rehabilitation programme is "CARF" accredited. CARF (Commission for Accreditation of Rehabilitation Facilities) is the international standard of accreditation and best practice in medical rehabilitation services. CARF is based on the standards developed by multidisciplinary specialist rehabilitation and is consistent with "Model systems of care for TBI. The NRH is continuing to pursue further specialist accreditation for all to the rehabilitation programmes at NRH including CARF accreditation for the individual brain injury, spinal cord injury, amputee and paediatric family centered care rehabilitation programmes.
- The NRH has limited capacity to meet the needs of patients requiring acute inpatient rehabilitation services. The new hospital project to be built on site at NRH is designed to provide an essential increase in bed capacity for TBI patients and has been designed in line with National and International standards of medical rehabilitation facilities.

RECOMMENDATIONS

- Expansion of current in-patient ABI capacity in line with recommendations in the 'New National Rehabilitation Hospital' plan.
- Development of acute and intensive Brain Injury Rehabilitation beds as outlined in the NRH@Beaumont unit plan.
- Expansion of current Neuro-behavioural unit as per the 'New National Rehabilitation Hospital' plan. The experienced gained over the past 14 years has enabled NRH to develop a unique range of skills and expertise in challenging behaviour. With that background, the NRH has a gained a unique perspective in this complex area of service delivery.
- Close collaboration with Continuing Care and Rehabilitation Services Providers such as Peamount and Royal Hospital, Donnybrook.
- Close collaboration with the Voluntary Agencies and community ABI service providers including PBF, Headway, SEABI team and other rehabilitation care providers such as St. Doolagh's and Redwood.
- The rehabilitation component of the Irish Heart Foundation submission to the Cardiovascular Strategy Implementation Group should be incorporated as an integral component of the National Rehabilitation Strategy.

CONCLUSION

Ireland has the foundation, people, and skills to build on existing services and plan for effective ABI rehabilitation within the HSE framework as part of the health care continuum. Best practice and the highest international standards are both cost effective and cost efficient. Rehabilitation delivered in a poorly coordinated, manner by multiple independent agencies is costly both in the short and long term due to inefficient utilisation of resources and poorer outcomes which ultimately leads to inappropriate delay in transfers between services and fewer individuals with ABI returning to independent home, community and work settings.

Health care professionals, health care administrators, and the HSE by building on existing rehabilitation expertise, delivering on planned rehabilitation facilities and services, can implement a co-ordinated and effective strategy. A coordinated system of care will drive the further change needed to maximise the use of available resources for the most benefit. International best practice is of proven effectiveness in delivering a co-ordinated rehabilitation service. Best practice reduces morbidity, improves patient outcomes, and recognises that, for sustainability, cost efficiency and cost effectiveness are paramount.

Spinal Cord System of Care Programme (SCSC) at NRH

Services for those with spinal cord injury in Ireland are, in the main, provided by the Mater Misericordiae University Hospital (MMUH) and the National Rehabilitation Hospital (NRH). The NRH has been providing a spinal injury service since 1963. The Mater Hospital has managed the acute phase since 1991 and the NRH provides a comprehensive, follow on, inpatient and out patient rehabilitation service.

As a national service the NRH accepts referrals from every part of the country although the majority of patients are referred from the acute Spinal Injury Centre at the Mater Hospital. Since 2007 the Scope of the Spinal Cord System of Care at NRH has expanded to include spinal cord dysfunction. Spinal cord dysfunction may result from traumatic injury or non traumatic injury including for example, cancer involving the spinal cord or demyelinating disorders.

The spinal injury programme at the NRH is a Complex Specialised Rehabilitation Service (C-SRS). It spans the continuum of acute to community and is designed to provide international best practice in line with 'Model Systems' of care for SCI. (The USA's National Institute on Disability and Rehabilitation Research (NIDRR) 'Model Systems' are specialised programmes of care in spinal cord injury and traumatic brain injury which gather information and conduct research with the goal of improving long-term functional, vocational, cognitive and quality-of-life outcomes for individuals with disabilities in these areas. (USA Department of Education 2008))

Incidence

O' Connor & Murray (2005) estimated the incidence of SCI in Ireland as being 13.1 per million population based on National Rehabilitation Hospital figures for the year 2000. However current expert opinion estimates are higher than this with Ireland estimated to fall somewhere in the middle of international estimates (12-40 per million) with approximately 27 per million population per year. This would equate to 120 new Spinal Cord Injuries per year based on a population of 4.5 million (traumatic and non-traumatic). The number of 116 persons admitted to NRH in 2008 does not include the patients discharged directly home from the Mater or other acute centres. At a minimum this figure indicates Ireland in line with international estimates of 25 per million with the actual figure being significantly greater.

UK incidence figures for traumatic injury are quoted as approximately 10-15 people per million populations per year. In 2008, 60 persons with traumatic spinal cord injury were admitted to NRH giving an average for 2008 of 13 people per million of population. Including both traumatic and non traumatic injury, 116 persons had a first admission to the NRH spinal rehabilitation programme in 2008. A further 40 patients were readmitted for secondary rehabilitation.

Life expectancy for people with a SCI has improved significantly in recent years and currently it is approximately 70-90% of normal life expectancy (McCormick 2006). Persons with SCI require a life long service. There are currently nearly 1500 individuals with a Spinal Cord Injury (SCI) in Ireland.

SERVICES PROVIDED - SPINAL CORD SYSTEM OF CARE PROGRAMME (SCSC)

Each person receives a preadmission assessment of medical and rehabilitation needs that includes diagnosis, prognosis, morbidity, co-morbidity, premorbid level of function, mental status, ability to tolerate the intensity of the care and support systems. If a person meets the programmes admission criteria, the person can be offered the service. Persons admitted and their families are offered appropriate information and opportunity for feedback at every stage of the process, and are actively

involved in decisions regarding their care. An important aspect of this programme is education of both patient and family in relation to primary prevention to avert reoccurrence of the impairment process and secondary prevention related to potential risks and complications due to impairment.

Following admission the interdisciplinary team members, in collaboration with the patient and family, will develop a comprehensive treatment plan that addresses the identified needs of the person, their family and support network.

Types of services offered in the Spinal Cord System of Care to meet these identified needs could include:

- Activities of daily living training
- Adaptive equipment assessment and training
- Assistive technology assessment and training
- Audiology screening
- Behavioural training
- Bowel and bladder training
- Clinical psychological assessment and intervention
- Communication assessment and management
- Coping and adjustment to disability
- Dentistry
- Discharge planning
- Driving and community transport assessments and training
- Dysphagia assessment and management
- Family and caregiver training and education
- Fitness and sports
- Hydrotherapy
- Independent living assessment
- Information regarding entitlements and services.
- Medical management
- Mobility training
- Nutritional counselling and management
- Occupational therapy
- Orthopaedic assessment
- Orthotics and splinting
- Pastoral and spiritual services
- Patient Advocacy Service
- Patient and family support system counselling
- Pharmaceutical Care
- Physiotherapy
- Podiatry
- Prosthetics
- Psychosocial assessment and intervention
- Radiology
- Referral to appropriate care pathway supports
- Rehabilitation nursing
- Respiratory therapy
- Safety awareness and training
- Sexuality and fertility counselling
- Skin care training
- Spasticity and pain management
- Urology service
- Vocational assessment

Some persons admitted to more than one programme in the NRH will receive appropriate services from each programme. Depending on the assessed needs, some services cannot be provided on site within the Spinal Cord System of Care. If additional services are needed and not available on site, the programme can facilitate referral for certain ancillary services.

Examples of these ancillary services could include:

- Fibreoptic endoscopic examination of swallow (FEES)
- Neurology
- Optician / orthoptics
- Substance abuse counselling
- Video fluoroscopic swallowing evaluation

Services Provided for Families/Carers/ Support Systems:

Families and carers are partners in the rehabilitation process and are encouraged to participate in all phases of the programme. Information, counselling, emotional and psychological support can reduce the emotional sequelae experienced by the family/carer. This support may help them to adapt and come to terms with the life changes, and so result in better long-term outcomes for both the patient and the family. Many services are available within the Spinal Cord System of Care to meet the needs of the patient's family to include:

- Education about spinal cord dysfunction.
- Education on what typically happens for families / carers who have been affected by spinal cord dysfunction
- Annual joint presentations with the voluntary agency Spinal Injuries Ireland.
- Psychological support
- Pastoral services
- Peer support through interaction with other families
- Psychosocial assessment and intervention
- Family / support system counselling
- Information about support and advocacy resources, local accommodation and assistive technology resources.
- Short stay on site facility for family / carers to trial living independently with patient (Villa Maria)

Post Discharge Services:

Urology

The Urology service at the National Rehabilitation Hospital is a national service currently provided via sessional commitment by a Consultant Urologist based in the Adelaide and Meath and National Children's Hospital (AMNCH) and assisted by the Nursing Department at NRH.

In the past renal failure was the leading cause of death in the spinal cord injured (SCI) population. The death rate from renal causes in the 1960's was reported to be between 37% and 76%. Renal complications now rank 10th (3.6%) as a primary cause of death in patients with a spinal cord injury. This improvement is largely attributed to the co-ordinated medical, specialist nursing and rehabilitation care.

International data would suggest that spinal cord injured patients should have follow up at a minimum on an annual basis. The Urology service at the NRH includes:

1. A Consultant led clinic on a weekly basis and two nurse led clinics on weekly basis (The annual surveillance carried out in these clinics ensures that any red-flags indicating urological complications are identified in a timely manner. This number is expected to increase as the spinal injury population in Ireland grows.) **On average 700 patients attend this clinic on an annual basis.**
2. An informal countrywide telephone service is available on a daily basis for spinal cord patients and their families/carers, general practitioners, and public health nurses. **On average over 150 telephone calls are received on a monthly basis.**
3. A nurse-led catheter clinic is held for patients requiring the first change of supra-pubic catheter and for patients requiring education and training on catheter care. Supra-pubic catheterization is a commonly recommended means of bladder management for patients requiring a long-term indwelling catheter. Patients discharged from the National Rehabilitation Hospital may experience difficulties in getting supra-pubic catheters changed in the community as many General Practitioners, Public Health Nurses, and Registered General Nurses are not educated and competent to carry out this procedure. **Patients report on a regular basis that they have to endure an average of three to nine hours round trip to their local Accident & Emergency Department to have their catheters changed.** The Clinical Nurse Manager has provided training on a national basis to General Practitioners, Public Health Nurses, and Registered General Nurses, relatives, and carers.

Outpatient Clinic

The Outpatient service at the NRH runs a weekly comprehensive interdisciplinary clinic for both new and review patients with approximately 10 persons attending each week and seeing on average 400 persons each year. The current minimum waiting time for the outpatient clinic is 4 to 5 months

National Nursing Liaison Service

The Spinal Liaison Nurse Service endeavours to bridge the gap between the hospital, home and the health care professionals. In order to prevent complications such as pressure sores and help manage bowel and bladder problems (Up to 85% of individuals with SCI develop a pressure ulcer at some time in their life, accounting for one fourth of the cost of caring for a patient with a spinal cord injury, (Byrne& Salzberg, 1996)) individuals should be visited in their own home by a Spinal Liaison Nurse at 6 weeks post discharge and then at 6 months, followed by yearly visits if required, depending on level of injury.

The Spinal Liaison Nursing Service also serves as a resource to local primary care teams with access to specialised knowledge regarding the condition and needs of patients with spinal cord injury.

The Spinal Liaison Nursing Service was reduced to half time in April 2006, as a result there were no home visits for 20 months. In 2008 this half time position was filled and 149 patients were seen in their own homes nationwide. As of January 2009 there are currently 58 patients in Dublin that are awaiting a home visit and 100 patients nationwide. Additional hours are required to get the service up to speed and allow visits to occur and allow the service to develop further. The Spinal Unit in Oswestry, UK, admits on average 100 spinal patients every year and they employ three full time Liaison Nurses this compares to only one Spinal Liaison Nurse for all of Ireland.

Vocational Rehabilitation Programme

The Vocational Programme is a case managed service specifically designed to address the vocational needs of persons with spinal cord injury. The team includes the client, representatives from the HSE, FAS, NRH staff and the voluntary organisation SII. This service is available for two years post discharge.

RECOMMENDATIONS

Delayed Discharges

Unfortunately during 2008 the 'delayed discharges' statistics in the Spinal System of Care Programme accounted for over 65% of the total delayed discharges for all programmes in the NRH in the past year. The average length of stay (LOS) for persons with SCI in NRH in 2008 was 120 days. For those discharged with complex needs in 2008 the average LOS was 215 days, with 7 patients over 300 days and one patient discharged after a 760 day admission with a delay of 628 days.

LOS in NRH for some persons with complex spinal cord injury could be dramatically reduced leading to reduction of waiting times in acute hospitals and increased patient throughput in the NRH. The accommodation difficulty of transitioning to the community for persons with complex disability is reviewed in the joint report by Citizens Information Board / Disability Federation of Ireland 'The Right Living Space'. **A funded strategic relationship between an appropriate voluntary agency and the NRH could address the usual chief barriers to discharge, addressing both housing and care needs. The cost saving for the health system and the increase in quality of life for individuals would be considerable.**

Patients needing Anaesthetic cover

Patients with higher respiratory needs could be admitted earlier to the NRH with the provision of on-call anaesthetic cover at the NRH and appropriate staff education. Currently anaesthetic service needs are met on an individual sessional basis.

Satellite and Rapid Review Clinics

In the UK the model of local satellite clinics is being used. In this model, the consultant and a therapy staff member travel to review complex patients who would otherwise need to travel a great distance. Local nursing staff, therapy staff, carers and families assist and gain valuable experience in spinal cord injury care and treatment.

Due to the current waiting for Outpatient appointments, an increase in capacity and the provision of a rapid review clinic would enable community, primary healthcare teams, to access early assessment of the person from the community.

Specialty Accreditation

The quality of care at NRH was accredited in 2008 by CARF (Commission on Accreditation of Rehabilitation Facilities) which is the premier international, independent rehabilitation accreditation service. The Spinal Cord System of Care Programmes at the NRH is currently accredited as part of the overall inpatient programme. The Spinal Cord System of Care Programme will be pursuing individual 'specialty accreditation' within the next 3 years. This speciality accreditation reflects best practice as indicated in the 'Model Systems' of care and is essential to ensure quality service provision in rehabilitation services.

Appendix 6

Prosthetic, Orthotic and Limb Absence Rehabilitation (POLAR) Programme

The Prosthetic Rehabilitation Service with the Spinal Rehabilitation service formed one of the two original rehabilitation programmes at Our Lady of Lourdes Hospital on the Rochestown Avenue site. This later became the National Rehabilitation Hospital. As such, the experience with Prosthetic rehabilitation goes back many decades to the early 1960s with several thousand patients having been successfully rehabilitated after often devastating, but always life-changing, limb loss.

The only Institution of its kind in Ireland, it is also the only Consultant led Prosthetic rehabilitation service in the country with a single Consultant overseeing the service that includes 20 inpatient beds at the NRH, a weekly or twice weekly outpatient clinic, and daily Prosthetic reviews and appointments. There are two Consultant attended clinics at Cork and Galway on a monthly basis. These clinics and the other satellite clinics at Waterford (with telemedicine facilities), Letterkenny, Sligo, Carrick-on-Shannon and Castlebar are run every two weeks with senior prosthetists from the NRH and Opcare (the NRH's strategic partner in delivering prosthetic and orthotic services) in attendance. Local workshops provide a same-day facility for minor repairs and adjustments.

The NRH is a Public Service fully funded by the HSE. This is also an internationally accredited service which, in the next two years, will be applying for Speciality CARF Accreditation for the POLAR (Prosthetic Orthotic and Limb Absence Rehabilitation) Programme (CARF – Commission for Accreditation of Rehabilitation Services).

Referral to the Service

Every amputee should have access to a Consultant led team in Amputee Rehabilitation whether prostheses are ultimately appropriate or not.

The demand and a responsive model of care

There are several models of care available from the United States, Australia and Canada. However, this document considers the model in the UK, given the readily available statistics and their not unreasonable applicability to the Irish situation. Detailed reports are also available and included with this submission (BSRM Amputee and Prosthetic Rehabilitation – Standards and Guidelines 2nd Edition October 2003; Ireland falls within a similar off-Continental Europe location as the UK and has good examples of service already available on the island of Ireland in the Amputee Rehabilitation Centre in Belfast.

For a population of about 65 million in the UK, there are about 65,000 patient records open in the Disability Centres. This does not take into account those with amputations *and no prosthetic requirement*. The prevalence of a condition without a high early mortality is likely to be significantly more than the average annual incidence, currently about 6500 new referrals a year (NASDAB 2003) in the UK.

In Ireland, this could mean for a population of about 4 million, a prevalence of about 4000 with limb absence and prosthetic requirements. There is no data available on the number of new amputations annually. The NRH has about 4500 open files at any given time. In 2008 we had 2780 clinic attendances and 372 lower limbs were manufactured (more than one limb could be manufactured for the

same patient per year, as could two limbs and more be manufactured for each bilateral amputee); 65 upper limb prostheses were also manufactured. The figure for 2007 was 431 new limbs manufactured. This is therefore, only the tip of the ice-berg.

Therefore the number of nationwide new amputations annually would be in excess of the numbers manufactured at the NRH. A conservative estimate is likely to be about 500 per year, of which the NRH would only be referred a selection. While there is Prosthetic provision in the country separate from the NRH, this is an unregulated and unknown entity and not part of a comprehensive rehabilitation service.

SERVICES PROVIDED – PROSTHETIC, ORTHOTIC AND LIMB ABSENCE REHABILITATION PROGRAMME

Each patient receives a preadmission assessment of medical and rehabilitation needs to identify their unique medical, physical, cognitive, psychological, social, behavioural, vocational, educational, cultural, family, spiritual and leisure/recreational needs. Admission to the service is dependent on meeting the admission criteria. The person served and their families are offered appropriate information and opportunity for feedback at every stage of the process, and are actively involved in decisions regarding their care. The patient and their family are offered education regarding prevention of complications and management of risk factors such as diabetes and vascular disease.

Following admission the interdisciplinary team members in collaboration with the patient and family, develop a holistic treatment plan incorporating the services that address the identified needs of the person, their family and support network.

Persons admitted to the POLAR programme receive a minimum of two hours of direct services per day, Monday to Friday. Direct service intensity varies on weekends depending on resources available, and therapeutic weekend leave may be incorporated into the rehabilitation programme to facilitate translation of functional gains into the home environment and the gradual reintegration of the person into their home and community.

Services offered in the programme to meet these identified needs include:

- Activities of Daily Living training
- Assistive technology
- Audiology screening
- Cognitive training
- Coping and adjustment to disability
- Dental services
- Discharge Planning
- Driving and community transport assessments and training
- Dysphagia assessment and management
- Family and caregiver training and education
- Fitness and Sports
- Hydrotherapy
- Independent living assessment
- Information regarding entitlements & services
- Medical management
- Mobility training
- Nutritional counselling & management
- Orthopaedic assessment
- Orthotics & splinting
- Pastoral and spiritual services
- Patient Advocacy Service
- Patient and family support system counselling
- Pharmaceutical Care
- Plastic surgery assessment
- Podiatry/Chiropody
- Prosthetic assessment and management
- Psychiatric assessment
- Psychological assessment and psychotherapy
- Psychosocial assessment & intervention
- Radiology Services
- Rehabilitation nursing
- Relaxation and stress management
- Respiratory therapy
- Safety awareness and training
- Sexuality counselling
- Skincare training
- Smoking cessation counselling
- Urology service
- Vocational assessment and counselling

Persons admitted with dual diagnoses may receive services from other specialty programmes as required.

If additional services are required and not available on site, the programme facilitates referral to the appropriate ancillary services.

Examples of these ancillary services include:

- Endocrinology
- Fibreoptic Endoscopic Evaluation of Swallowing (FEES)
- Neurology
- Oncological services
- Optician
- Substance abuse counselling
- Vascular surgery
- Videofluoroscopic swallowing evaluation

Medical specialists in anaesthetics, orthopaedics, plastic surgery, psychiatry, radiology, respiratory and urology are consulted as required.

The Services Provided For The Families/Carers/Support Systems Of the Person Served

Families and carers are partners in the rehabilitation process and are encouraged to participate in all phases of the programme. Information, counselling, emotional and psychological support can reduce the emotional sequelae experienced by the family/carer. This support may help them to adapt and come to terms with the life changes, and so result in better long-term outcomes for both the patient and the family.

Many services are available within the POLAR programme to meet the needs of the patient's family including:

- Education about limb loss that may include group sessions, printed material, informal instruction and practical skills training in preparation for discharge
- Counselling services
- Psychological services
- Pastoral services
- Peer support through interaction with other families and through local and international support groups (Amputee Ireland, Disability Ireland, REACH, Limbless Association, STEPS, IWA)
- Information about support and advocacy resources, local accommodation and assistive technology resources.
- Short stay transitional living in an on-site support facility.

There are several strengths already inherent in the NRH model of Prosthetic Rehabilitation. Two of these will be discussed in more detail.

A. The role of the NRH as a National (supra-regional) Centre of Excellence.

The NRH is more than a Limb Fitting Centre. Prosthetic rehabilitation goes way beyond a limb fitting exercise. **'Wholistic' Amputee Rehabilitation** for the non-prosthetic user would typify such an approach.

As the majority of amputees are elderly and dysvascular, with an ageing population, the numbers will increase year on year. The co-morbidity in these people is self-evident. Secondary prophylaxis in this visibly identifiable and captive cohort of amputees is essential, either as stand-alone good clinical practice or as part of a National Strategy for Cardiovascular disease, Diabetes, Elderly Care and Stroke similar to the National Service Frameworks in the UK.

Rehabilitation services have an essential role in **primary prevention**.

Prosthetic services in the UK are provided through NHS Trust Hospitals, either as regional, supra-regional or local and visiting services [Prosthetic Advisory Group to Minister for the Disabled A report of the Working Party (Chair Carter-Jones, L) College of Occupational Therapists; 1994].

Several publications support the recommendation that Rehabilitation services for those with limb loss should remain a **Specialised Rehabilitation Service** (defined as a multi-disciplinary service having input from a Consultant in Rehabilitation Medicine) [Turner Stokes L. Implementation of Clinical Governance in Rehabilitation Medicine: The state of the Art 2002. Clinical Rehabilitation 2002; 16(Suppl.1):9-11].

These services should be commissioned at a level above that of the equivalent of a Primary Care Trust. This could be for a population the size of the average *new* Strategic Health Authority, roughly about 5 million people (DoH Statistics, UK, July 2006), akin to the population of Ireland but relevant only as a comparable population estimate. The more useful comparison is linked to the actual access to services and their delivery in a timely, cost-effective and regulated manner, allowing for urban/rural splits, etc.

Nevertheless, this seems to be the level at which one could justify a single Supra-regional centre with regional centres linking in to this central service. The NRH, in Ireland, is eminently placed to be such a centre of excellence.

Several reports from the UK would support a supra-regional service [HSC 1998/198 – Commissioning in the New NHS, DoH 1998; **Amputee rehabilitation** – recommended Standards and Guidelines. London 1992. Available from the British Society of Rehabilitation Medicine; **Congenital Limb deficiency** – recommended standards of care, London: 1997; Department of Health, **Amputee Care**- Guidelines for Commissioners. Prosthetic Strategic Supply Group, Procurement and Supplies Agency, Nov 2001; Department of Health, **Specialised Services** definition supplement to HSC 1998/198, DoH December 2001; Medical Rehabilitation for people with physical and complex disabilities. **Royal College of Physicians' Committee** on Rehabilitation medicine London 2000; Audit Commission – 'Fully equipped', London 2000]

The justification for a Supra-regional service is several-folds:

- The average number of Amputees for a single service is likely to be small, for example, the Mercy Hospital in Cork would have about 30 amputations per year (personal communication). In comparison, the NRH sees about 350 amputations a year and has about 4500 patient files open at any time.
- Large, expensive and technically sophisticated clinical and workshop facilities are essential to support the service and are costly to duplicate, staff and maintain
- A high level of specialist and professional expertise is required in medical, prosthetic, technical and therapy staff. This already exists at the NRH but developing the NRH as a National Centre for Excellence will obviate the need to send patients abroad for costly rehabilitation, necessarily distant from the context in which these people's lives unfold.
- As exposure to prosthetic rehabilitation does not form part of an undergraduate medical curriculum, developing resources to teach, demonstrate skills, design audits and foster collaborative research would be diluted if these were to be spread across several regions. The NRH already provides the only training for future Therapists and Consultants with an interest in Amputee Rehabilitation. There is an unmet need for developing national fora for Counsellors and Specialist Nurses. The NRH is well placed to deliver on this.
- A **'critical' mass** of patient population through specialist services is essential for achieving and maintaining high standards and cost effectiveness. The exact number of patients is not known due to lack of any data available. Extrapolating from other services is also likely to prove misleading. There are 44 Limb Fitting Centres in the UK (BSRM Oct 2003) each receiving, on average, 130 patients a year. About 90% of these will be lower limb amputations (NASDAB 2001). It is reasonable to presume that patients with 'standard amputations' (unilateral below knee) could be managed at regional centres, given time, with adequate provision and cyclical training of staff over a period of about 5-7 years.
- Any National Centre, like the NRH, must have the capacity and capability in resources to be able to withstand this transfer of specialist skills without imploding. Personnel 'seconded' to the regional centres should do so without affecting the service at the NRH which must be supported to meet this challenge.
- What is reasonably certain is that specialist scenarios will all fall within the remit of a centre skilled in dealing with such patients over decades - the NRH. Examples of these include:
  1. Low volume, highly emotive, potentially litigious upper limb loss (fewer than 5% of total amputations nationally in the UK)
  2. Multiple limb loss (17 cases in the UK in 2001 for a population of 60m)
  3. Congenital limb deficiency – either in isolation or part of other system involvement
  4. Children with acquired limb absence
  5. Special circumstances like pregnancy
  6. Combined disability – limb loss and a stroke or as part of poly trauma with brain injury
  7. 'Amputee PLUS' situations like severe phantom pain, complex regional pain syndromes, severe psychological sequelae, psychiatric co-morbidity with limb loss as part of deliberate self harm.

- Data are sparse in Ireland unlike the NASDAB (National Amputee Statistical Database) in the UK. Not all patients with amputations are referred for limb fitting. The NRH can and should, with adequate resources, be the National centre collating the incidence and prevalence of limb absence, providing the HSE with statistics reflecting local and regional variations in demand and providing the State with a database and expertise to help shape policy and assist the State in meeting its statutory obligations, for example, EPSEN 2004, Disability Act 2005. **The 'unreferred' person with limb absence** is an unfathomed entity.
- The incidence of limb absence is higher in homeless people, those in prison, those on the street begging, in immigrant populations (the demographics are changing) and in the Forces. A single National Centre obtaining and acting on this data would better serve this **vulnerable population**.
- **Patient choice should be a real choice**. The development of a National Centre for Excellence will always provide the valuable 'second' opinion within the country, arbitrating in cases of sufficient complexity, allocation of scarce and competing resources and acting as a Body to which independent 'appeal' can be made. It would be unnecessary to refer these patients on to the UK, Sweden or the USA as is current practice. Awareness in the amputee population of a shortfall in capacity within the system at present sometimes undermines clinical credibility. The 'best' treatment always happens to be outside Ireland, which it shouldn't.

B. The existence and further development of the 'Hub and Spoke' model for service delivery at the NRH

The same reports quoted above, in the UK recommended the development of a hub and spoke model of service delivery, where the regional and local services established themselves with focused clinical leadership and forged affiliations for further specialisations with tertiary referral centres. The document 'Amputee and Prosthetic Rehabilitation –Standards and Guidelines' published by the British Society of Rehabilitation Medicine (BSRM) in 2003 (updates in 2008), strongly recommended this model.

The NRH already has well established fortnightly Clinics at Waterford (with Tele-medicine facilities back to the NRH), Cork (likely to increase to weekly clinics and even a permanent presence), Letterkenny, Sligo, Carrick-on-Shannon, Castlebar and Galway. Patients seen at the NRH for inpatient rehabilitation are followed up at these clinics as well as 'Primary' amputees newly referred by the local hospitals. A Consultant presence at Cork and Galway on a four to six weekly basis ensures clinical input and an essential contact for the patient. Links are being developed with the local Hospitals in Cork and a common Amputee Rehabilitation Pathway is being agreed.

This strategy ably exemplifies the **HSE Transformation Programme** (2007-2011) whereby access to care and services are provided in a setting closer to the patient's home. Travel times in rural Ireland can be taxing for the elderly amputee and their carers.

Joint specialist clinics (for example, Orthotics) with Vascular Surgery, Orthopaedics and Paediatrics are all examples of seamless working from the pre-amputation stage, through the post-amputation pre-prosthetic stage to the stage of prosthetic rehabilitation. The majority of dysvascular amputees rarely have just the single amputation and the patient with diabetes and single limb loss never has another 'normal' limb. Resources are needed to pursue these Joint clinics making use of available clinic slots and Consultant visits. Access to expertise does not have to be Dublin-centric.

The services of the NRH, already in place, need to be enhanced and developed.

The NRH model of Amputee and Prosthetic Rehabilitation provides a robust template against which to style future developments in the National Plan and Strategy for Rehabilitation. Existing structures need to be updated, consolidated and be injected with increased capacity.

The present resources are at full stretch and glued together by good will. An inter-disciplinary Consultant led service is the key to managing a long-term condition effectively, efficiently and empathetically in an exemplary evidence-based manner.

RECOMMENDATIONS

- Improved access for all irrespective of age, diagnosis, prognosis or postcode
- Consolidating and improving the service models already in place
- Developing new services as detailed
- Developing National specialist services
- Responding to clinical need with an increased **capacity and capability** to deliver
- **To Match availability** of new technologies and, sometimes inappropriate demand for these, **with astute clinical applicability** of these technologies, making it patient centered, and cost-effective
- Establishing a national resource – data, expertise, consultancy, appeal and a Centre for Excellence
- To assist the State in fulfilling its statutory obligations, help shape policy, provide best practice guidelines, develop national service frameworks and advise on manpower allocation
- Rehabilitation, Habilitation and Enablement are examples of thorough and wise medicine. It is not cheap. While costly, it can be made more cost effective and provide value for money. The benefits in the long run justify the initial front-ended costs (Lynne Turner Stokes). While the person with an amputation or limb absence may not have the same catastrophic effects of a brain or spinal cord injury, their circumstances are unique, personal, and strike at the core of their identity and bodily integrity. They are also more likely to get back to previous levels of productivity, employment and social re-integration (Department of Work and Pensions UK 2007) and should be afforded every chance to do so. This is the ultimate aim of Rehabilitation – the resumption of desired roles within a meaningful life.

Paediatric Family-Centred Rehabilitation Programme

The Paediatric Family-Centred Rehabilitation Programme is the national medical service for children and adolescents requiring a Complex Specialised Rehabilitation Service (C-SRS) as a result of traumatic and non-traumatic brain injury, stroke, traumatic and non-traumatic spinal cord injury, neurological disorders, limb absence, other musculoskeletal and neuromuscular disorders.

Along with the other programmes in the NRH, the Paediatric Service is accredited by CARF (Commission for Accreditation of Rehabilitation Facilities) and meets the internationally recognised rehabilitation standards for Comprehensive Integrated Inpatient Rehabilitation Programmes (CIIRP).

International perspective/Models of Care

It is difficult to find services providing "generic" paediatric rehabilitation programmes for a population and county similar in size to that of Ireland. Most services in the US or UK would be ABI or spinal cord injury specific. Two current reference frameworks for the delivery of services that are relevant to our situation in terms of population however can be found in Australia.

1. In 2006 the Children, Youth and Women's Health Service in South Australia (population of 1.5 million) formed an interagency group to develop a Paediatric Rehabilitation Services Plan for 0 – 18 year olds only. (Paediatric Rehabilitation Service Planning – Sally-Anne Nicholson).

   They identified six areas of reform covering an integrated service framework, child and family centric services, key transition points, information exchange, emerging interventions and workforce development. The NRH Paediatric Programme demonstrates the same holistic approach and ambition to work seamlessly with dedicated community services.
2. The Victorian* Paediatric Rehabilitation Service(VPRS) in Australia(*population 5 million) began in 2005 to "specifically cater for children and adolescents who, as a result of injury, medical/surgical intervention, or functional impairment, will benefit from a program of developmentally-appropriate, time-limited, goal-focused multidisciplinary rehabilitation".

   The VPRS description of inpatient services could compare to those provided by the NRH and those aspired to in relation to outreach.

A very significant area for health promotion generally is for the so called "mild" ABI . **Developing a RED FLAG early warning system**, as recommended by Mark Ylvisaker and Tim Feeney in the U.S. would be a valuable national investment. Children with "mild" ABI often have no physical deficits but can present with a myriad of problems such as poor attention and concentration, problems with processing information and impulsive behaviour. Many of these children remain undiagnosed having been discharged from acute hospitals or are later misdiagnosed with ADHD and other such conditions. A significant number of people in prison* have a history of mild or moderate brain injury in childhood and early intervention may have helped to prevent such an outcome.

(Pat Mottram – 2007- on study of HMP Liverpool, Styal and Hindley – sampled 2,298 prisoners and found 48% reported head injury).*

SERVICES PROVIDED – PAEDIATRIC FAMILY-CENTRED REHABILITATION PROGRAMME

A pre-admission assessment is carried out to determine that the child or adolescent meets the admission criteria and to schedule their admission taking into account their needs, the waiting list for the service and the availability of resources.

The Paediatric Team carries out –

- Assessments
- Goal Planning
- Treatment
- Education, and,
- Discharge Planning

- for the rehabilitation needs of each individual child/adolescent taking into account their individual levels of impairment, their current and potential levels of activity and their ability and willingness to participate in the programme available.

Assessments address the needs of each child/adolescent according to their age, stage of development, their family and cultural background. The initial and ongoing assessments, include the following -

- Behaviour
- Cognition
- Communication
- Community
- Education/vocational
- Emotional
- Family
- Physical
- Sexual

Based on the initial and ongoing assessments, and with consideration of the child's/ adolescent's and family's cultural background, the individual plan addresses, as appropriate, the needs in the following areas:

- Activities of daily living
- Adjustment of the child/adolescent to the activity limitation
- Adjustment of the family to the activity limitation
- Assistive technology
- Bereavement/grief/coping
- Communication
- Community and school reintegration
- Driver evaluation and education
- Environmental modifications
- Growth and development
- Health education
- Learning
- Mobility
- Nutrition
- Play and leisure
- Reproduction
- Safety
- Sexuality
- Socialisation
- Spirituality
- Substance abuse
- Vocational
- Wellness

Education on-site for the Paediatric Service

The Department of Education and Science provide schooling onsite for all children and adolescents (4 – 18years) attending the service as day and inpatients. This service is integral to the rehabilitation process.

Staff in the school

- Principal
- Special Duties Teacher
- Outreach Teacher (12.5 hrs p.w.)
- Special Needs Assistants x 2
- School Secretary (7 hours p.w.)

(The school also has access to a Special Education Needs Organiser through the Department of Education and Science).

Other services available on-site include

- Audiology screening
- Discharge Liaison Occupational Therapists (Dublin Area only)
- Driving assessment
- Neurology
- Orthopaedic surgery – consultations only here
- Patient Advocacy Service
- Respiratory therapy
- Seating
- Splinting
- Vocational Assessments

Off-site Services

All other Paediatric sub-specialist services are available via referral to the tertiary National Childrens' Hospital.

Services offered to Family/Carers and Patient Support Systems

To meet the objectives of the Paediatric Family-Centred Rehabilitation Programme information, education and counselling is offered individually or in groups. Psychosocial assessments and interventions are offered on an individual basis.

Information regarding entitlements, services and referrals to appropriate care pathway supports is also available.

Referrals for the inpatient service are received from across the Republic of Ireland and sometimes from other countries when Irish citizens have suffered a serious injury abroad. The referrals are for children and adolescents deemed to require a multi-disciplinary assessment and intensive rehabilitation intervention by a team experienced in the treatment of the patient groups noted above. The level of intervention required and experience of the treating team would not be available in community services.

The NRH inpatient paediatric programme is available over 5 days – Monday to Friday – for eight patients at any one time (six beds and two therapeutic day places). Weekends are typically spent at home for the young person's essential rest and to continue with a home programme of activities. Where children are unable to go home because of the level of care required in the early stages of rehabilitation they are facilitated to remain in hospital for the weekend.

Where children and adolescents require intensive inpatient services over an extended period they will mostly attend Monday – Friday for 3 weeks and then be at home for the fourth week to again rest and practice individually identified therapeutic activities of daily living. This regular time at home is designed to help the patient and their family regroup and to begin to reintegrate with the wider community.

Children and adolescents can also be offered 2 or 3 days per week inpatient attendance if they and their family/carer are:

- Preparing/trial-ing for discharge and transition home
- Are unable to commit for a full 5 day week because of fatigue, age or for other family reasons.

This arrangement of split weeks allows for a fuller utilisation of the Paediatric services – e.g. two small fatigued children with an ABI can share the one week of therapies or the team can use part of the week to bring back young patients in need of review of their rehabilitation needs (see more details under "Outreach/Follow-up/Review/ Outpatient section).

Following an individualised assessment and goal planning process the inpatient child/adolescent will receive direct therapeutic intervention, over and above the nursing and medical care, ranging from 1.30 – 4.30 hours per day depending on their age and ability to participate. School is also available for those patients between 4 – 18 years of age with skilled and experienced teaching staff able to meet the individual special learning needs of each child (ranging from 1.30 – 3.00 hours per day)

The paediatric therapeutic team is a small group i.e. 1 WTE post for physiotherapy, occupational therapy, speech and language therapy, medical social work and 0.6 for Psychology, 0.1 for music therapy.

Admissions for 2008

The paediatric team worked with 33 children and young people with a new ABI and 50 other patients were admitted for review or a neuropsychological assessment (some of the children reviewed may have had more than one admission).

There were 4 new spinal injury patients admitted and 8 others reviewed.

Three new patients with limb absence were admitted and 20 others reviewed.

Outreach/Follow-up/Review/ Outpatient Services

The paediatric team is experienced at planning for the child/adolescent's discharge and transition from inpatient care to their home, community and local school. Along with preparing the family/carers for the return home, training is offered by the team to school staff to help prepare them for the needs of the young person. This is an important aspect of the process but can be a pressure for staff in the hospital, taking them away from the delivery of direct therapy, and for local school personnel particularly if they are a small school with few staff to cover absences from the classroom.

The Department of Education and Science have recognised the need to provide an Outreach service to children/adolescents who are transitioning from rehabilitation to local school. For the purpose of offering support and education to school staff the D.E.S. has sanctioned 12.5 hours per week to the NRH school to enable this vital link in the rehabilitation process to take place. This initiative has been welcomed by schools, parents and students and has led to increased and more beneficial participation of students in education.

Current local/primary care community services taking on rehabilitation from the NRH request information and education both at the time of discharge/transition and also post discharge. They look to the NRH paediatric team for guidance and recommendations regarding treatment because of the complex rehabilitation critical mass experience and because of the changing and emerging needs of the young people.

When a child or adolescent has a brain injury, the insult is superimposed on a developing brain where basic skills such as reading and social skills may not have been laid down. Some of the resulting difficulties, known as "sleeper effects" only emerge as the child matures and fails to reach developmental milestones in line with their peers. It has been hypothesised that children with certain injuries may "grow into" the deficits acquired as a result of the trauma (Chapman & McKinnnon, 2000).

Timely specialist inter-disciplinary reviews of the needs of children and adolescents with these chronic care conditions is essential and a long-term perspective as to their changing needs is required. Transition from primary to secondary school for example, when the young person is confronted with new challenges and increasingly more complex tasks is often a crisis point. Building and retaining skills and experience in a range of community services for the complex injuries is difficult and therefore linkage/integration with the tertiary paediatric rehabilitation service is essential.

Currently the NRH paediatric programme offers a review service to the following past patients (all under 18 years) – ABI - 140, Spinal Injury - 15, Neurology - 17, limb absence – 36. There are some 30 additional patients who require transfer and introduction to adult services.

Reviews are planned on an individual basis or in peer groups for children and adolescents confronting similar challenges in their rehabilitation pathway.

Outpatient services are limited - the O.T. service has 3 hours per week for limb absence outpatient clinics. The social work department has 0.2 of its 1 WTE earmarked for outpatient work but they and all other disciplines, particularly neuropsychology, undertake significant outreach, liaison and follow-up.

Community Services/Continuum of care/Networks

The availability of services in the community for children discharged with continuing rehabilitation needs is very inconsistent. A variety of organisations take referrals across the country e.g. Enable Ireland in Galway, Cope in Cork and Early Intervention in Clare. All have different abilities to respond and allocate services. Some have waiting lists for services of 18 months.

Discharges from the NRH can be delayed when services are not available or the level of service required is not available. Discharging children who have achieved their rehabilitation goals to the point where they could be maintained and continue to improve if they could receive weekly input from local services is not an easy outcome to achieve. Deciding therefore to discharge a child who needs weekly input knowing that this will not be available presents the team with an ethical challenge.

RECOMMENDATIONS

Children and adolescents admitted to the NRH present with the most complex rehabilitation needs requiring high levels of skilled therapeutic input. Where children can be assessed and then returned to their community services with the appropriate level of therapy this is done. No child/family wants to be separated from home unnecessarily. Parents have work commitments and responsibilities to other family members/dependants so those children and adolescents who are admitted to the NRH are admitted because they are in need of the intensive skilled therapeutic input that is unavailable elsewhere.

The improvements and benefits of increased bed availability (an increase from the current therapy services for 8 patients to 20, plus from a 5 day service to a 7 day service), better separate/adjacent child/adolescent focused facilities and more staffing promised in the new hospital project is greatly anticipated. Waiting times for admission would be reduced, the necessary reviews could be more effectively and reliably managed and the needs of the different age ranges catered for. Expecting teenagers and two years olds to share the same physical spaces is outdated, especially as we know now that adolescents progress faster in health care settings that are adolescent focused. Vulnerable sixteen to eighteen year olds would also, with the additional beds in the new hospital, not need to be placed around the hospital on adult wards as at present.

The provision of a dedicated interdisciplinary paediatric **Outreach** service is a most necessary important development to enhance rehabilitation services for children and adolescents in Ireland. This would allow therapists to go out from the specialist service to work with the family and with community services, plus take on some of the regular reviews in the community. It would relieve pressure on the inpatient service and facilitate education and training in the community. Parents report that returning home after rehabilitation can be the most stressful of times post injury/serious illness.(See "Living with an acquired brain injury during childhood and adolescence: An Irish Perspective)

Pre-school play and education for young children attending the NRH is currently not available. Parents identify this as a major gap in the services within the hospital and additional resources are needed to meet this need in the future.

The introduction of a Music therapy service in 2008 has been very positively welcomed by patients, families and staff. The service is for 1 day per week only and is supported through donations to the National Medical Rehabilitation Trust Limited. Establishing this as a permanent therapy available to the patients into the future is a goal for the further development of holistic rehabilitation services.

In the coming months the team will be working towards a specialist Paediatric Family-Centred **CARF** accreditation application thereby meeting further internationally recognised standards for paediatric rehabilitation.

We recommend that any rehabilitation facility be similarly accredited to ensure excellence in service provision.

A **RED FLAG early warning system**, should be developed as recommended by Mark Ylvisaker and Tim Feeney in the U.S .

Reference List

1. Horn, Lawrence Systems of Care for the person with Traumatic Brain Injury Traumatic Brain Injury 1992; 3: 475-492
2. Turner-Stokes L. Rehabilitation following acquired brain injury: national clinical guidelines. Turner Stokes L, editor. London: British Society of Rehabilitation Medicine/Royal College of Physicians, 2003.
3. Turner-Stokes L, Williams H, Abraham R, Duckett S. Clinical standards for inpatient specialist rehabilitation services in the UK. Clin Rehabil 1999; 14:468–80.
4. Turner-Stokes L, Williams H, Abraham R. Clinical standards for specialist community rehabilitation services in the UK. Clin Rehabil 2001; 15:611–23.
5. World Health Organisation. International classification of functioning, disability and health. Geneva: WHO, 2002.

National Rehabilitation Hospital

UNDER THE CARE OF THE SISTERS OF MERCY

Rochestown Avenue, Dun Laoghaire, County Dublin

Tel: (01) 235 5000 Fax: (01) 285 1053 Web: www.nrh.ie

DESIGNED AND PRODUCED BY BEGLEY HUTTON, DUBLIN WWW.BEGLEYHUTTON.COM FRONT COVER PHOTOGRAPHY BY LORCAN BRERETON